



## DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

### Doctorate in Clinical Psychology: Main Research Portfolio

**1) Critical Review of the Literature: The psychological mediating factors between childhood maltreatment and eating disorders: a systematic review; 2) Service Improvement Project: Team formulation in recovery teams: staff perspectives and recommendations for team managers and psychologists; 3) Main Research Project: Parental illness perceptions in Type 1 Diabetes and JIA.**

Harris, Madeline

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# Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Madeline Harris

Doctorate in Clinical Psychology

University of Bath  
Department of Psychology

May 2018

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# Abstracts

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## **Critical Review of the Literature**

The consequences of childhood maltreatment are pervasive and implicated in the development of a range of mental health difficulties, including eating disorders. However, the mechanisms which mediate the link between childhood maltreatment and eating disorders are unknown. This has important implications for effective intervention, as eating disorders are notoriously difficult to treat. There are numerous factors which predict poor therapy outcome that overlap with mediators between childhood maltreatment and disordered eating behaviours in non-clinical samples. This may suggest people with a history of maltreatment could be at greater risk of developing an eating disorder which does not respond to currently available interventions. This review aimed to identify the mediating variables between childhood maltreatment and eating disorders. Studies which tested mediators of the relationship between childhood maltreatment and eating disorders were systematically reviewed and a narrative synthesis of the findings reported. The findings suggested mediators of the relationship between childhood maltreatment and eating disorders could be mapped onto cognitive-emotional-behavioural and affective models of eating disorders. Limitations of the reviewed studies and clinical implications are discussed.

## **Service Improvement Project**

Formulation, in the context of clinical psychology, involves integrating a breadth of knowledge to create a tentative hypothesis to describe the difficulties service users may experience. Team formulations, created by a multi-disciplinary team to construct a shared understanding of a service user's experiences, can facilitate a more consistent and collaborative approach within a team and lead to a more holistic, psychosocial understanding of a person's difficulties. This project was carried out in two recovery teams in a locality within an NHS trust in which staff had been trained to use the 5 Ps model of formulation (Weerasekera, 1995). The project aimed to establish whether staff were using 5 Ps formulations in their work, whether these were experienced as useful, what supports staff to use a 5 Ps formulation, and what staff feel the barriers to using a 5 Ps formulation are. A questionnaire and two focus groups were used and analysed using descriptive statistics and thematic analysis. The results suggested staff used the model to inform their clinical

thinking, in consultation with therapist colleagues, and in group reflective practise. Overall, the 5 Ps model was well received. The model appeared to support staff both with their clinical work and to be more reflective and holistic in their approach. However, staff did raise some drawbacks with the model and difficulties with integrating it consistently into their clinical practise. Service recommendations include areas for continued practise, areas for development and change, and areas for further service evaluation and potential research opportunities.

## **Main Research Paper**

The ‘Common Sense Model’ (CSM; Leventhal, Meyer, & Nerenz, 1980) aims to explain how psychological factors influence long-term health condition (LTC) management. Research has shown the CSM applies to children and young people (CYP) as well as adults. However, the model does not incorporate systemic factors, which are especially relevant for CYP, for whom families hold more illness management responsibilities. Caregiver perceptions of an illness have been linked with outcomes for the person with the health condition. Other factors which have been shown to affect illness perceptions include the LTC itself. This pilot study examines differences in illness perceptions between two groups of parents: those whose children had type 1 diabetes, and parents of children with juvenile idiopathic arthritis. This study also examined mood, anxiety and time since the child’s diagnosis as predictors of parental illness perceptions. It was found that having a child with type 1 diabetes was predictive of anticipating longer illness duration and perceiving greater control over the condition. Additionally, having greater levels of anxiety was predictive of more perceived control, which may be associated with condition monitoring behaviours in type 1 diabetes. Finally, scores indicating lower mood predicted perceiving the consequences of the condition as more severe and lower levels of perceived control over the condition. Future research directions and clinical implications are discussed.

# Critical Review of the Literature

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## **The psychological mediating factors between childhood maltreatment and eating disorders: a systematic review**

Madeline Harris

M.G.Harris@bath.ac.uk

Department of Clinical Psychology

University of Bath

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### **Internal Supervisor**

Dr James Gregory | J.D.Gregory@bath.ac.uk

### **External Supervisor**

Dr Felicity Cowdrey | Felicity.Cowdrey@nhs.net

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### **Intended Journal for Submission**

European Eating Disorders Review

This journal was chosen as it welcomes reviews on topics relating to clinical work with eating disorders. Author guidelines can be found in Appendix A.



## **Introduction**

### **Childhood Maltreatment**

Child maltreatment encompasses physical abuse, sexual abuse, emotional or psychological abuse, and neglect in those under 18 (World Health Organisation, 2002). The prevalence of childhood maltreatment is difficult to establish, due in part to underreporting (Wildeman et al., 2014). Worldwide, approximately one in four adults were physically abused as children, and one in five women have experienced childhood sexual abuse (World Health Organisation, 2016).

The consequences of childhood maltreatment can be numerous and pervasive. The physical sequelae of child maltreatment are well documented and there are many studies demonstrating the impact of childhood maltreatment on brain development (Twardosz & Lutzker, 2010). In addition, childhood maltreatment is associated with increased rates of mental health problems in adulthood including depression, anxiety, post-traumatic stress disorder (PTSD), eating disorders, behavioural disorders, drug use and suicidal behaviour (Meadows, Tunstill, George, Dhudwar, & Kurtz, 2011; Norman et al., 2012). As well as increased rates of mental health problems in those who have experienced maltreatment, research suggests experiences of maltreatment in childhood may also contribute to developing interpersonal difficulties, poor emotion regulation, dissociation, attentional difficulties, unhelpful thought processes, poor impulse control, and a disrupted sense of self (D'Andrea, Ford, Stolbach, Spinazzola, & Van Der Kolk, 2012). These psychological responses may explain in part the relationship between maltreatment in childhood and elevated mental health difficulties in adulthood. The present review aims to specifically investigate this possibility in relation to childhood maltreatment and eating disorders.

### **Childhood Maltreatment and Eating Disorders**

Eating disorders are typified by altered eating related behaviours which have a significant impact upon physical and psychosocial functioning (World Health Organisation, 1992). Anorexia nervosa (AN) is characterised by excessive weight loss due to dietary restriction with or without compensatory behaviours. In bulimia nervosa (BN), individuals experience episodes of binge eating followed by purging behaviour. Binge eating disorder (BED) is also characterised by binge eating but, unlike in BN, individuals do not engage in purging behaviour to compensate for the binge. Studies with community samples have demonstrated that most people who experience eating disorder symptoms do

not fit into the diagnoses above but instead have similar clinical features with different combinations and frequency of symptoms (Machado, Machado, Gonçalves, & Hoek, 2007; Turner, Bryant-Waugh, & R., 2004). Therefore, most people seen in outpatient clinical practice are diagnosed with Other Specified Feeding or Eating Disorder (OSFED) (previously Eating Disorder Not Otherwise Specified (EDNOS); Fairburn & Cooper, 2011). Irrespective of diagnosis, eating disorders are associated with poor health outcomes including increased mortality rates (Smink, Hoeken, & Hoek, 2012). Despite significant advancement in psychological theory and the development of evidence-based interventions, eating disorders remain difficult to treat, relapse is common and a significant proportion of people with an eating disorder go on to have a chronic course (Keel & Brown, 2010). Understanding the factors that contribute to the onset and maintenance of eating disorders and developing effective interventions is therefore a priority.

Historically, the evidence for a link between childhood maltreatment and eating disorders was mixed (Smolak & Murnen, 2002). However, recent reviews support the proposed link between historic childhood maltreatment and the development of eating disorders (Molendijk, Hoek, Brewerton, & Elzinga, 2017; Pignatelli, Wampers, Lored, Biondi, & Vanderlinden, 2016; Trottier & MacDonald, 2017), although there is a suggestion this association may be stronger with BN and BED than for AN (Caslini et al., 2016). Taken together with the literature concerning the range of responses to maltreatment, people with eating disorders who have also experienced childhood maltreatment may experience a wide range of other physical and psychological difficulties, and the relationship between these factors and the eating disorder symptoms is likely to be complex. Therefore, psychological models and interventions for people with eating disorders need to account for the range of difficulties and complex interactions that may exist in those who have also experienced childhood maltreatment.

There are a range of models and interventions available for people with eating disorders. The transdiagnostic cognitive-behavioural model of eating disorders proposes that over-evaluation of shape and weight control is central to the maintenance of eating disorders (Fairburn, Cooper, & Shafran, 2003). The importance placed on shape and weight control is proposed to drive weight loss behaviour, such as dietary restriction, which in turn contributes to other eating disorder symptoms such as weight loss, binge eating, and purging. Therefore, the intervention based on this model, known as 'Enhanced' Cognitive Behavioural Therapy (CBT-E), focuses on eating related behaviour change as well as other maintaining factors such as body image concerns, low self-esteem and interpersonal difficulties. Whilst CBT-E has a reasonable evidence-base (e.g. Fairburn et

al., 2009), the approach has been critiqued for failing to adequately consider affective components of eating disorders in sufficient depth (Fox & Power, 2009). Corstorphine (2006) proposed that problems with affect regulation and alexithymia can be important in the maintenance of eating disorders, and without addressing these components the success of an intervention is likely to be limited. Therefore, interventions are recommended with an emphasis upon improving emotional awareness, understanding, and management prior to engaging in more in-depth cognitive and behavioural work around the eating disorder (Corstorphine, 2006). Similarly, Waller, Corstorphine and Mountford (2007) posited that an invalidating childhood environment can influence core belief and schema development. Eating disorder symptoms therefore function to defend the individual from such beliefs by blocking emotions when they are either at a conscious (a 'chaotic dissociative' type) or unconscious level (a 'detached alexithymic' type). Based on this conceptualisation, Waller et al. (2007) proposed an effective eating disorder intervention would need to address these protective strategies, beliefs around emotions, and core beliefs, as well as work on the eating disorder presentation itself. Finally, affective components to eating disorder presentations have also been considered from a compassion-focused perspective, and Compassion Focused Therapy for Eating Disorders (CFT-E; Goss & Allan, 2010) explores the relevance of shame and self-criticism in eating disorder presentations. These alternative formulations of eating disorders, which consider the role of broader cognitions about the self, affective components, and interpersonal relationships in greater depth, may be important when working with people who have experienced childhood maltreatment. Therefore, for individuals with a history of maltreatment and eating disorder symptoms, a broader formulation and treatment strategy may be required to address the range of cognitive and affective processes which may be contributing to the onset and maintenance of the eating disorder.

People with eating disorders and a history of maltreatment are likely to have complex presentations, which may have implications for therapy outcomes (Briere, 2007). Psychological models and interventions for people with eating disorders therefore need to account for aetiological factors such as childhood maltreatment. Identifying the mediators of this relationship could therefore contribute to greater understanding of how maltreatment and eating disorders are related and improve psychological interventions for this group of patients. In the context of this review, mediating variables are the mechanisms by which an experience of childhood maltreatment is thought to lead to the development of disordered eating.

## **Mediators of the Relationship between Childhood Maltreatment and Disordered Eating**

Many studies have examined the relationship between maltreatment and disordered eating patterns in non-clinical populations and have attempted to identify possible mediators of this relationship. Some identified mediators in the literature are general psychological constructs or concomitants of maltreatment, such as negative affect or low mood (Dubosc et al., 2012; Mazzeo, Mitchell, & Williams, 2008; Michopoulos et al., 2015), anxiety (Cook-Cottone et al., 2016; Kent, Waller, & Dagnan, 1999; Mazzeo et al., 2008), PTSD (Dubosc et al., 2012; Holzer, Uppala, Wonderlich, Crosby, & Simonich, 2008) and general distress (Harned & Fitzgerald, 2002; Hund & Espelage, 2005, 2006; Thomas, Kelly, Chan, & Williams, 2017). Some mediators identified overlap to an extent with Fairburn's (2003) cognitive-behavioural perspective, including negative self-perception (Hymowitz, Salwen, & Salis, 2017), thin ideal internalisation (Vartanian, Foreich, & Smyth, 2016), drive for thinness (Rojo-Moreno et al., 2013), body image (Preti, Incani, Camboni, Petretto, & Masala, 2006; Williams & Gleaves, 2003), and self-esteem (Harned & Fitzgerald, 2002). Constructs identified by Corstorphine (2006) and Waller et al. (2007) have also explored as possible mediators, including maladaptive schemas (Jenkins, Meyer, & Blissett, 2013), emotional dysregulation (Burns, Fischer, Jackson, & Harding, 2012; Michopoulos et al., 2015), alexithymia (Mazzeo et al., 2008; Minnich, Gordon, Kwan, & Troop-Gordon, 2017), dissociation (Kent et al., 1999; Rodriguez-Srednicki, 2002), chaotic family environment (Hastings & Kern, 1994), and behavioural impulsivity (Dworkin, Javdani, Verona, & Campbell, 2014; Wonderlich et al., 2001). Affective mediators including depression, shame (Murray & Waller, 2002) and specifically body-related shame (Duarte, Pinto-Gouveia, & Stubbs, 2017; Tripp & Petrie, 2001), have also been identified as mediators in the existing literature which maps onto affective models of eating disorders (Fox & Power, 2009; Goss & Allan, 2010).

### **Summary and Current Review**

There are numerous factors predictive of poor therapy outcome that appear to overlap considerably with the mediating variables identified in the literature between maltreatment and disordered eating (Halmi, 2013). Taken together, this suggests those who have a history of maltreatment in childhood may be at greater risk of developing an eating disorder which does not respond to current available interventions. It is therefore imperative to understand the mechanisms by which childhood maltreatment can lead to an eating disorder, to target these mechanisms with an appropriate intervention. This

systematic review therefore aims to identify the variables found in the literature to mediate the relationship between childhood maltreatment and eating disorders.

## **Method**

### **Protocol and Registration**

The protocol for the review was registered on PROSPERO after database searches and prior to abstract screening (PROSPERO registration number: CRD42017080666).

### **Eligibility Criteria**

**Study Type.** Quantitative studies were included. Studies were excluded if they did not report primary data (e.g. a review, a book chapter), used only qualitative methods, or if they were case studies or series.

This review is concerned solely with studies which a priori identified and tested possible mediators between childhood maltreatment (IV) and eating disorders (DV). Studies were required to include a form of mediational analysis which included childhood maltreatment as the independent variable (IV), eating disorders as the dependent variable (DV), and a separate third mediating variable.

**Participants.** Participants were people with an eating disorder who had experienced childhood maltreatment.

The review will include studies which recruited people diagnosed with any eating disorder. This is because there are common features of eating disorders which occur transdiagnostically, and many people with a diagnosis of one eating disorder are likely to shift to another diagnosis at a later point ('diagnostic migration') (Fairburn et al., 2003). Eating disorders are defined in this review as anyone who meets the criteria outlined in the ICD-10, DSM-IV, DSM-IV-TR, or DSM-5. Studies which use earlier criteria were excluded, as there are substantial differences between DSM-IV (and later) criteria for eating disorders and those used prior, which may undermine the validity of the findings (Sunday et al., 2001).

Childhood maltreatment is defined as anyone who experienced maltreatment prior to 18 years of age. Maltreatment is defined by the World Health Organisation (2002) to include neglect and forms of physical, sexual, and emotional abuse. The definition of maltreatment used in this review does not require parental figures to be the perpetrators,

and can include behaviour perpetrated by peers which was experienced as abusive (e.g. bullying experiences). Bullying experiences meet the definition of maltreatment outlined by the World Health Organisation, and bullying experiences have been shown to be associated with trauma responses such as PTSD (Idsoe, Dyregroy & Idsoe, 2012), suggesting these experiences can be experienced as profoundly traumatic. There were no participant age restrictions.

**Outcome.** To satisfactorily establish a variable as a mediator of a relationship between two other variables, several criteria should ideally be met. Kazdin (2007) suggested these criteria should include a strong association between the independent, dependent and mediating variables, and for this association to demonstrate specificity and consistency. The role of a mediating variable should be established using experimental manipulation, be evident through a timeline in which independent and mediating variables preceded the onset of dependent variables, and demonstrate a gradient in which a greater amount of the mediator will lead to a greater change in outcome. Finally, theoretical plausibility as to how the mediator operates is required.

There are numerous methods used in the literature to establish mediation statistically. A common approach is known as the causal steps approach (e.g. Baron & Kenny, 1986). This method involves identifying the significance of each path in the mediation model, and then establishing the effect of the mediator by examining the relationship between X and Y when taking account of M. This method is widely used in the literature but has attracted some critique. This method is thought to be low in power in comparison with other methods, and consequently runs the risk of a higher type II error rate. It has also been critiqued for not directly measuring the effect of the mediator, and instead only inferring it from the relationships between other variables (Hayes, 2009; Perera, 2013). Some researchers have used a product of coefficients approach, such as a Sobel Test (Sobel, 1982, 1986), in conjunction with a causal steps approach in order to address the latter issue. Whilst this is a valid approach, the Sobel Test is based on an assumption of a normal sampling distribution around the mediator, and in practise this is often thought to be asymmetric (Hayes, 2009; Perera, 2013). Therefore, this means the assumptions inherent to the Sobel Test may be at risk of being violated. Alternative methods which claim to have greater power and directly test mediating variable(s) without assuming a normal sampling distribution have therefore gained interest in recent years. These include, but are not limited to, bootstrapping approaches (Preacher & Hayes, 2004), the Empirical M Test (Holbert & Stephenson, 2003), and the Phantom Model approach (Macho & Ledermann, 2011).

**Additional Criteria.** No publication date restrictions were used. Studies which did not have a version in English available were excluded as there was no funding available for translation.

## **Information Sources**

The databases searched were PubMed, APA PsycNet (specifically PsycINFO, PsycExtra, and PsycArticles), Embase, and Published International Literature on Traumatic Stress (PILOTS). These databases were searched on 8<sup>th</sup> November 2017. In addition, reference lists of the included studies were searched to identify any other relevant papers missed by database searches. In cases in which studies appeared to be relevant but insufficient data was recorded (e.g. in a poster presentation abstract), authors of the abstract were contacted directly for further information.

## **Search**

The search terms which formed the basis of each database search were as follows:

- Child Abuse, Child Neglect, Emotional Abuse, Sexual Abuse, Physical Abuse, Bullying, Domestic Violence
- Eating Disorder, Anorexia, Bulimia, Binge Eating Disorder, Binge/Binging, Purge/Purging, Avoidant Restrictive Food Intake Disorder (ARFID), Eating Disorder Not Otherwise Specified (EDNOS), Other Specified Feeding or Eating Disorder (OSFED)

These search terms were expanded based on preliminary literature searches to include all known terms used in the literature for similar constructs (e.g. child abuse, child maltreatment, ‘abused child’, child harm, childhood abuse, etc.). Both British and American spellings and possible alternative spellings of terms were included. All the databases included some form of thesaurus feature, and additional searches were made using these where applicable. The full search strategy for each database is in Appendix B.

## **Study Selection**

After duplicates were removed, the titles and abstracts generated by the database searches were screened by the first author. Of these, 10% were screened by an independent rater, and any discrepancies between reviewers were discussed. Studies that did not achieve a consensus between the two reviewers were included at the full text stage. There was substantial agreement between raters at this stage (Cohen’s  $\kappa=.626$ ,  $SE=.103$ ,  $p<.001$ ).

The full texts of potentially eligible studies were assessed for eligibility by the first reviewer and 10% of these were reviewed by an independent rater. Of these studies, there were no discrepancies between the decisions of the two raters. The reference lists were searched for any other potentially eligible papers missed by the database search strategy. All studies which passed the full-text screening stage were included in the final review.

### **Data Collection**

A data extraction table was developed for the purposes of the review. Extracted data included information on the participant sample, childhood maltreatment, eating disorders, mediational variables and analyses, funding information, and quality assessment. The lead author extracted data from all the selected studies, and an independent second-rater extracted data from 10% of the selected studies, and any discrepancies were discussed.

### **Quality Assessment**

Studies were assessed for quality using an adapted version of the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies published by the National Institutes of Health (NIH). This tool was chosen as it pertained closely to the types of studies included in the final analysis. The tool included items on research questions, study population and participants, sample size, number of measurement points, the validity and reliability of measures, blinding, follow up, and control of confounding variables. The tool was adapted to include an additional question regarding measurement of mediational variables, identical in wording to the existing items concerning the measurement of independent and dependent variables. The tool does not use a scale to provide an overall score, which is discouraged by The Cochrane Collaboration when assessing for risk of bias as this can reduce transparency (The Cochrane Collaboration, 2011). The lead author assessed the selected studies for quality, and a second rater similarly assessed 10% of included studies and any discrepancies between ratings were discussed.

### **Planned Methods of Analysis**

It was judged that there were insufficient numbers of eligible studies investigating mediational variables to warrant statistical aggregation. Consequently, a narrative synthesis was conducted.



## **Results**

### **Study Selection**

A flow diagram of the study selection results can be found in Figure 2. The database searches provided a total of 4503 records. After removal of duplicate papers, 2815 abstracts remained. In total, 2710 studies were discarded after screening the titles and abstracts of all records, leaving 105 studies to review at the full text stage. At this stage, 94 studies were excluded (see Figure 2 for exclusion reasons). The reference lists of selected studies were searched, and no additional studies were identified for inclusion. A total of 11 studies were included in the final analysis.

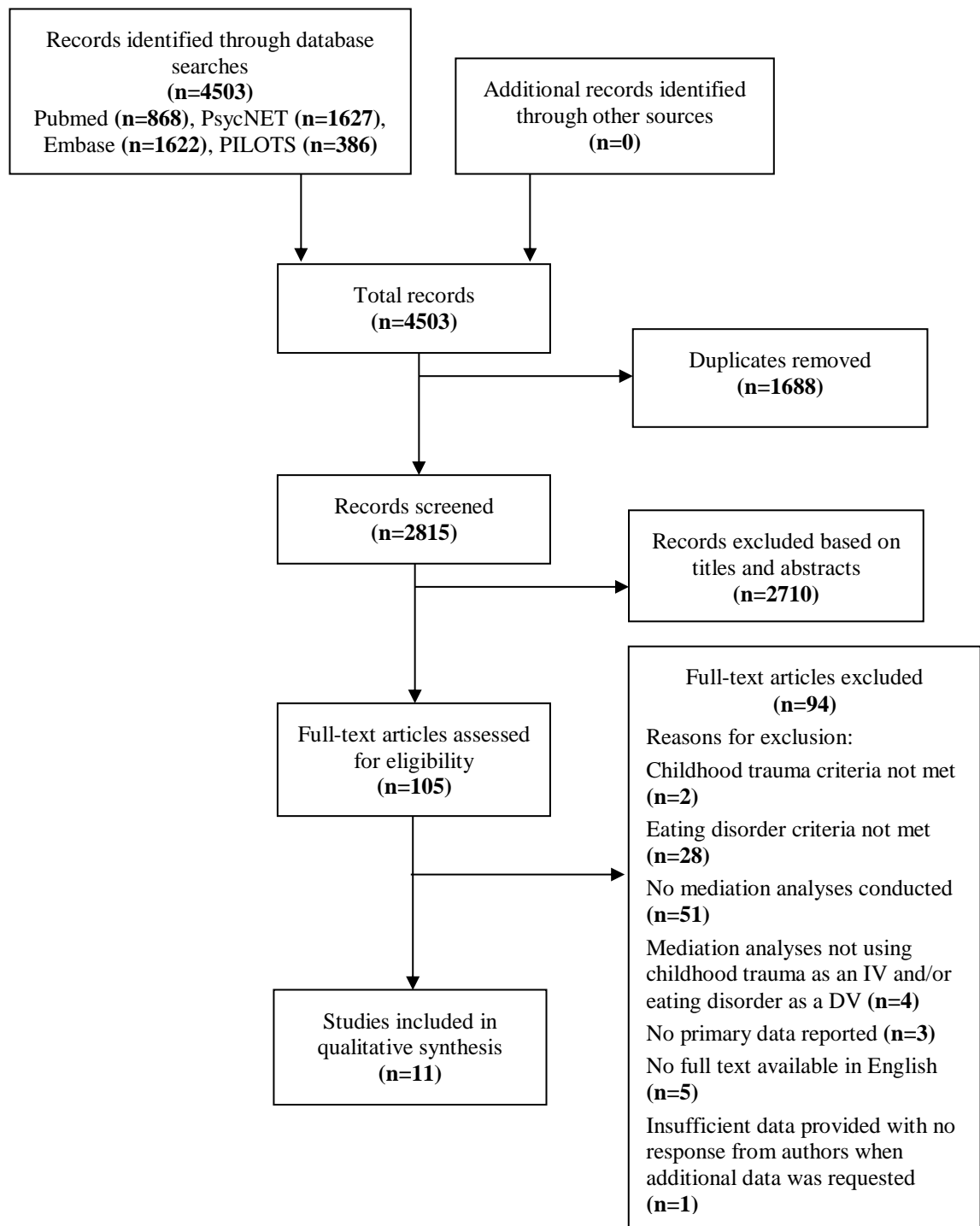


Figure 2. Flowchart depicting study selection process.

## Study Characteristics

The included studies spanned from 1995-2015 and included 1720 participants overall. Studies originated from the United Kingdom (n=3), the United States of America (n=3), Canada (n=3), Norway (n=1) and South Korea (n=1). Full details for each study can be found in Table 1.

**Participant characteristics.** The number of participants in the included studies ranged from 60 to 315. Ten studies provided data on age, and all these studies used adult

samples with a mean age in the range of 20-30 years. All studies reported data on gender, and samples consisted mostly of women, with seven studies made up entirely of all-female samples. Six studies reported on the ethnicity of participants, and these all had predominantly Caucasian participants. All 11 studies recruited from services which offered treatment for people with eating disorders. The two studies which included a non-clinical control group (Groleau et al., 2012; Steiger et al., 2011) recruited these participants using public and university-based advertising.

**Design of studies.** Two studies used a longitudinal design, and these both used within-group analyses (Craycraft, 2011; Vrabel, Hoffart, Rø, Martinsen, & Rosenvinge, 2010). The remaining studies used a cross-sectional design. Of these, two used a between-groups design (Groleau et al., 2012; Steiger et al., 2011) and the remaining seven used a within-groups design (Everill, Waller, & Macdonald, 1995; Hewett, 2014; Kong & Bernstein, 2009; Racine & Wildes, 2015; Sweetingham & Waller, 2008; Tasca et al., 2013; Waller et al., 2001).

**Mediation.** Eight studies (Craycraft, 2011; Groleau et al., 2012; Hewett, 2014; Kong & Bernstein, 2009; Steiger et al., 2011; Sweetingham & Waller, 2008; Vrabel et al., 2010; Waller et al., 2001) used a causal steps method of mediational analysis (Baron & Kenny, 1986). Of the remaining studies, one (Racine & Wildes, 2015) used the PROCESS model (Hayes, 2013), one (Tasca et al., 2013) used a bootstrap procedure (Shrout & Bolger, 2002) and the phantom model approach (Macho & Ledermann, 2011), and one (Everill et al., 1995) used ANCOVA.

**Childhood maltreatment variables.** Four studies looked at sexual abuse (Craycraft, 2011; Everill et al., 1995; Vrabel et al., 2010; Waller et al., 2001). One (Sweetingham & Waller, 2008) looked at peer teasing in childhood. The remaining six studies investigated more than one kind of abuse (Groleau et al., 2012; Hewett, 2014; Kong & Bernstein, 2009; Racine & Wildes, 2015; Steiger et al., 2011; Tasca et al., 2013).

Maltreatment was assessed using a variety of different methods. Six studies used self-report questionnaires (Groleau et al., 2012; Hewett, 2014; Kong & Bernstein, 2009; Racine & Wildes, 2015; Steiger et al., 2011; Tasca et al., 2013). Three studies assessed historic maltreatment using a semi-structured clinical interview (Everill et al., 1995; Sweetingham & Waller, 2008; Waller et al., 2001). The remaining two studies established a history of maltreatment by reviewing participants' medical records (Craycraft, 2011; Vrabel et al., 2010).

**Eating disorder variables.** Eight studies used a sample which consisted of a range of eating disorder diagnoses. Of these, one study included people who had a diagnosis of

BED (Waller et al., 2001), with the rest including a participants with diagnoses of AN, BN and EDNOS. These studies did not conduct subgroup analyses between the different diagnoses. Of the remaining studies, one had a sample consisting only of people with a diagnosis of AN (Racine & Wildes, 2015), and two with participants only with a diagnosis of BN (Groleau et al., 2012; Steiger et al., 2011).

Self-report measures of eating disorder behaviours and cognitions were used in ten of the studies. The remaining study (Waller et al., 2001) used diary records of bingeing and purging behaviour as their dependent variable. One study (Everill et al., 1995) used both self-report measures and behavioural measures.

**Mediators.** The included studies measured a wide range of possible mediating variables. Four studies measured depression (Groleau et al., 2012; Kong & Bernstein, 2009; Steiger et al., 2011; Waller et al., 2001). Two studies measured each of the following mediators: dissociation (Everill et al., 1995; Waller et al., 2001), ineffectiveness, which can be defined as a person's sense of personal inadequacy in relation to the world, (Craycraft, 2011; Groleau et al., 2012), affective instability (Groleau et al., 2012; Steiger et al., 2011), and attachment (Hewett, 2014; Tasca et al., 2013). Only one study examined each of the following variables: perfectionism (Groleau et al., 2012), body image disturbance (Hewett, 2014), obsessive-compulsive symptoms (Kong & Bernstein, 2009), emotional dysregulation (Racine & Wildes, 2015), behavioural instability and sensation seeking (Steiger et al., 2011), shame and social anxiety (Sweetingham & Waller, 2008), avoidant, borderline and obsessive-compulsive personality disorders (Vrabel et al., 2010) and abandonment and mistrust/abuse core beliefs (Waller et al., 2001). These mediators were assessed using a breadth of different self-report measures, full details of which can be found in Table 1.

Table 1.

*Characteristics of included studies.*

Study	Sample	Design	Eating Disorder Variables	Maltreatment Variables	Mediation Variables	Author Conclusions
Craycraft (2011)	<p><b>Number of participants:</b> 150 <b>Age:</b> M=26 (SD=8.19; Range 18-55) <b>Gender:</b> 100% female <b>Ethnicity:</b> Caucasian (N=145), Asian American (N=1), Hispanic (N=1), Native American (N=1) and Unknown/Mixed (N=2) <b>Country:</b> USA</p>	Longitudinal, within group	<p><b>ED population:</b> Diagnosis of anorexia nervosa (AN), bulimia nervosa (BN), or eating disorder not otherwise specified (EDNOS). Diagnosis information retrieved from medical records. <b>Measures:</b> EDE-Q 4</p>	<p><b>Maltreatment type(s):</b> Sexual abuse <b>Measures:</b> Retrieved from medical records</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986) <b>Mediating Variable(s) (and how measured):</b> Ineffectiveness (Ineffectiveness subscale of EDI-2)</p>	<p>No correlation between sexual abuse and ED symptoms 1 year post admission (<math>r(87)=-.03</math>, <math>p=.79</math>). Further analysis re. mediation therefore not conducted. No funding source declared.</p>
Everill, Waller, & Macdonald (1995)	<p><b>Number of participants:</b> 60 <b>Age:</b> M=22.8 (SD=6.27) <b>Gender:</b> 100% female <b>Ethnicity:</b> Not reported <b>Country:</b> UK <b>BMI:</b> M=21.7 (SD 4.01)</p>	Cross-sectional, within group	<p><b>ED population:</b> AN (N=5), AN of the bulimic subtype (N=10), BN (N=30), BN with a history of anorexia (N=15) <b>Criteria:</b> DSM-IV <b>Measures:</b> Frequency of bulimic behaviours (bingeing and vomiting); EAT-26</p>	<p><b>Maltreatment type(s):</b> Historic sexual abuse <b>Measures:</b> Clinical interview</p>	<p><b>Method of Mediation Analysis:</b> ANCOVA <b>Mediating Variable(s) (and how measured):</b> Dissociation (DES-II)</p>	<p>Dissociation is a mediating factor in the relationship between historic sexual abuse and bingeing in people with eating disorders No funding source declared</p>
Groleau et al. (2012)	<p><b>Number of participants:</b> 315 (Eating Disorder (ED') group (N=176); 'Normal Eater' (NE') group (N=139)) <b>Age:</b> ED group M=24.95 (SD=5.52); NE group M=23.91 (SD=5.62) <b>Gender:</b> 100% female <b>Ethnicity:</b> Not reported <b>Country:</b> Canada</p>	Cross-sectional, between groups	<p><b>ED population:</b> BN - 69.9% BN-Purging subtype, 7.4% BN-Nonpurging subtype, 19.3% EDNOS binge-purge subtype, 1.1% EDNOS purge only subtype, 2.3% EDNOS binge nonpurge subtype <b>Criteria:</b> DSM-IV <b>Measures:</b> EDE; EAT-26</p>	<p><b>Maltreatment type(s):</b> Physical, Sexual, and Emotional Abuse <b>Measures:</b> CTI</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986) <b>Mediating Variable(s) (and how measured):</b> Ineffectiveness (Ineffectiveness subscale of EDI-2) Perfectionism (Perfectionism subscale of EDI-2) Affective instability (Affective instability subscale of DAPP-BQ) Depression (CES-D)</p>	<p>Relationship between childhood emotional abuse and overall symptoms partially mediated by ineffectiveness Relationship between CEA and dieting fully mediated by ineffectiveness. Relationship between CEA and oral control was partially mediated by affective instability. Funding: Support from the Fonds de la Recherche en Santé du Québec and the Canadian Institutes for Health Research</p>

Study	Sample	Design	Eating Disorder Variables	Maltreatment Variables	Mediation Variables	Author Conclusions
Hewett (2012)	<p><b>Number of participants:</b> 83</p> <p><b>Age:</b> M=26 (SD=8.71; Range 18-54)</p> <p><b>Gender:</b> 100% female</p> <p><b>Ethnicity:</b> 75% Caucasian, 15% Latina, 1% African American, 1% Asian, 7% 'Other'</p> <p><b>Country:</b> USA</p>	Cross-sectional, within group	<p><b>ED population:</b> AN (restricting type N=19, purging type N=17) and BN (non-purging type N=7, purging type N=40). EDNOS (N=1) were excluded.</p> <p><b>Criteria:</b> DSM-IV</p> <p><b>Measures:</b> EDI-3</p>	<p><b>Maltreatment type(s):</b> Historic traumatic experiences</p> <p><b>Measures:</b> ACES, TSC-40, Keane PTSD scale on the MMPI-2</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986)</p> <p><b>Mediating Variable(s) (and how measured):</b> Attachment (RAAS) Body Image Disturbance (BSQ-34)</p>	<p>No mediating effects of attachment or body image between trauma symptoms and eating disorder pathology</p> <p>No funding source declared</p>
Kong et al. (2009)	<p><b>Number of participants:</b> 73</p> <p><b>Age:</b> M=23.9 (SD=4.82; Range 14-36)</p> <p><b>Gender:</b> 97.3% female</p> <p><b>Ethnicity:</b> Not reported</p> <p><b>Country:</b> South Korea</p> <p><b>Duration of ED:</b> M=3.6 years (SD=3.15)</p> <p><b>Frequency of binge episodes p/w:</b> M=21.46 (SD=5.66)</p> <p><b>Frequency purging episodes p/w:</b> M=28.43 (SD=11.55)</p> <p><b>BMI:</b> M=19.21 (SD=2.82; Range 13.7-25.7)</p>	Cross-sectional, within group	<p><b>ED population:</b> AN 39.7%, BN 53.4%, EDNOS 6.8%</p> <p><b>Criteria:</b> DSM-IV-TR</p> <p><b>Measures:</b> EDI-2</p>	<p><b>Maltreatment type(s):</b> Emotional abuse, physical abuse, sexual abuse, emotional neglect, physical neglect</p> <p><b>Measures:</b> CTQ</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986)</p> <p><b>Mediating Variable(s) (and how measured):</b> Depression (BDI) Obsessive-compulsion (MOCI)</p>	<p>Depression fully mediated the following relationships: physical neglect and drive for thinness, physical neglect and body dissatisfaction, emotional abuse and ineffectiveness, emotional abuse and interoceptive awareness, emotional abuse and impulse regulation, total EDI-2 and CTQ scores</p> <p>No funding source declared</p>
Racine & Wildes (2015)	<p><b>Number of participants:</b> 188</p> <p><b>Age:</b> Not reported</p> <p><b>Gender:</b> 95.7% female</p> <p><b>Ethnicity:</b> 95.2% Caucasian</p> <p><b>Country:</b> USA</p> <p><b>Source of sample:</b> ED inpatients and outpatients</p> <p><b>Duration of ED:</b> M=8.41 years (SD=8.87)</p>	Cross-sectional, within group	<p><b>ED population:</b> AN</p> <p><b>Criteria:</b> DSM-IV-TR criteria (with some participants not meeting the criteria for amenorrhoea or fear of fatness)</p> <p><b>Measures:</b> EDE</p>	<p><b>Maltreatment type(s):</b> Emotional abuse, Physical abuse, Sexual abuse</p> <p><b>Measures:</b> CTQ-SF</p>	<p><b>Method of Mediation Analysis:</b> PROCESS Model 4 (Hayes, 2013)</p> <p><b>Mediating Variable(s) (and how measured):</b> Emotional dysregulation (DERS)</p>	<p>Emotional dysregulation mediated the relationship between both emotional and sexual abuse and eating disorder symptom severity</p> <p>Funding: Supported by National Institute of Mental Health</p>

Study	Sample	Design	Eating Disorder Variables	Maltreatment Variables	Mediation Variables	Author Conclusions
Steiger et al. (2012)	<p><b>Number of participants:</b> 304 (Eating Disorder ('ED') group (N=174); 'Normal-Eater' ('NE') group (N=130))</p> <p><b>Age:</b> ED group M=25.95 (SD=6.36); NE group: M=24.79 (SD=6.34)</p> <p><b>Gender:</b> 100% female</p> <p><b>Ethnicity:</b> ED group - Caucasian 97.1%, Black 1.7%, Asian 0.6%; NE group - Caucasian 80.6%, Black 9%, Asian 10.4%</p> <p><b>Country:</b> Canada</p> <p><b>Duration of ED:</b> M=9.15 years (SD=6.60)</p>	Cross-sectional, between groups	<p><b>ED population:</b> BN</p> <p><b>Criteria:</b> DSM-IV-TR</p> <p><b>Measures:</b> EDE</p>	<p><b>Maltreatment type(s):</b> Sexual abuse, physical abuse</p> <p><b>Measures:</b> CTI</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986)</p> <p><b>Mediating Variable(s) (and how measured):</b> Stimulus seeking and affective instability (subscales of DAPP-BQ)</p> <p><b>Behavioural Impulsivity (Motor Impulsivity subscale of BIS)</b></p> <p><b>Depression (CES-D)</b></p> <p><b>BcII (DNA samples (in depth details available in the original paper))</b></p>	<p>Depression mediated the relationship between gene*abuse and bulimic status</p> <p>Gene*abuse interaction predicted bulimic status independent of affective instability, motoric impulsivity or sensation seeking</p> <p>Funding: Grants from the Canadian Institutes for Health Research</p>
Sweetingham & Waller (2008)	<p><b>Number of participants:</b> 92</p> <p><b>Age:</b> M=28.5 (SD=8.17; Range 18-58)</p> <p><b>Gender:</b> 100% female</p> <p><b>Ethnicity:</b> Not reported</p> <p><b>Country:</b> UK</p> <p><b>BMI:</b> M=22.1 (SD=7.71; Range 13-50)</p>	Cross-sectional, within group	<p><b>ED population:</b> AN (N=12), AN bingeing/purging subtype (N=7), BN purging subtype (N=25), BN non-purging subtype (N=7), EDNOS (N=41)</p> <p><b>Criteria:</b> DSM-IV</p> <p><b>ED measures:</b> EDI (drive for thinness, bulimia, body dissatisfaction subscales)</p>	<p><b>Maltreatment type(s):</b> Bullying/teasing - verbal bullying, physical bullying, teasing about appearance</p> <p><b>Measures:</b> Semi structured interview</p>	<p><b>Method of Mediation Analysis:</b> Baron &amp; Kenny (1986)</p> <p><b>Mediating Variable(s) (and how measured):</b> Shame (ESS)</p> <p><b>Social anxiety (Brief FNE)</b></p>	<p>Shame was a mediator between teasing by peers and the development of body dissatisfaction.</p> <p>Social anxiety does not mediate the relationship between verbal bullying by family and body dissatisfaction.</p> <p>No funding source declared</p>
Tasca et al. (2013)	<p><b>Number of participants:</b> 308</p> <p><b>Age:</b> M=27.17 (SD=9.44)</p> <p><b>Gender:</b> 96.4% female</p> <p><b>Ethnicity:</b> 88.5% Caucasian</p> <p><b>Country:</b> Canada</p> <p><b>Years diagnosed with ED:</b> M=7.95 (SD=7.46)</p> <p><b>BMI:</b> M=21.28 (SD=5.88)</p>	Cross-sectional, within group	<p><b>ED population:</b> AN (N=76), BN (N=104), EDNOS (N=127)</p> <p><b>ED measures:</b> EDE-Q 4</p>	<p><b>Maltreatment type(s):</b> Sexual abuse, 'punishment', neglect</p> <p><b>Measures:</b> CATS</p>	<p><b>Method of Mediation Analysis:</b> Bootstrap procedure (Shrout &amp; Bolger 2002), phantom model approach (Machio &amp; Ledermann, 2011)</p> <p><b>Mediating Variable(s) (and how measured):</b> Adult attachment (ECR)</p>	<p>Relationship between childhood trauma and eating disorder pathology is mediated by adult attachment anxiety and attachment avoidance.</p> <p>Both attachment anxiety and avoidance equally mediated the childhood trauma and eating disorder pathology relationship</p> <p>No funding source declared</p>

Study	Sample	Design	Eating Disorder Variables	Maltreatment Variables	Mediation Variables	Author Conclusions
Vrabel et al. (2010)	<b>Number of participants:</b> 86 <b>Age:</b> M=29.0 (SD=7.3) <b>Gender:</b> 99% female <b>Ethnicity:</b> 100% Caucasian <b>Country:</b> Norway <b>Duration of ED:</b> M=13.1 years (SD=7.3) <b>Duration of treatment at point of admission:</b> M=2.9 years (SD=2.1) <b>BMI:</b> M=20.2 (SD=4.8)	Longitudinal, within group	<b>ED population:</b> AN, BN, EDNOS <b>Criteria:</b> DSM-IV <b>Measures:</b> EDE	<b>Maltreatment type(s):</b> Sexual abuse <b>Measures:</b> Data collected retrospectively from medical charts	<b>Method of Mediation Analysis:</b> Baron & Kenny (1986) <b>Mediating Variable(s) (and how measured):</b> Personality Disorders (SCID-II)	No evidence that avoidant, borderline, or obsessive-compulsive personality disorders play a mediating role in the relationship between childhood sexual abuse and eating disorders No funding source declared
Waller et al. (2001)	<b>Number of participants:</b> 61 <b>Age:</b> M=25.3 (SD=4.30) <b>Gender:</b> 100% female <b>Ethnicity:</b> Not reported <b>Country:</b> UK <b>BMI:</b> M=23.6 (SD=4.68)	Cross-sectional, within group	<b>ED population:</b> BN (N=41), AN of the bulimic subtype (N=11), BED (N=9) <b>Criteria:</b> DSM-IV ED measures: diary records of binge/purge frequencies	<b>Maltreatment type(s):</b> Sexual abuse <b>Measures:</b> Clinical interview	<b>Method of Mediation Analysis:</b> Baron & Kenny (1986) <b>Mediating Variable(s) (and how measured):</b> Core beliefs (YSQ) Depression (BDI) Dissociation (DES-II)	Depression mediated relationship between childhood sexual abuse, two core beliefs (abandonment and mistrust/abuse), and frequency of bingeing Depression and dissociation mediated relationship between childhood sexual abuse, defectiveness beliefs, and frequency of vomiting. Depression mediated relationship between abuse and vomiting No funding source declared

Key for abbreviations:

**ACES** = Adverse Childhood Experiences Scale (Felitti et al., 1998); **AN** = Anorexia Nervosa; **BDI** = Beck Depression Inventory (Beck et al., 1961); **BIS** = Barrat Impulsivity Scale (Patton et al., 1995); **BMI** = Body Mass Index; **BN** = Bulimia Nervosa; **Brief FNE** = Brief Fear of Negative Evaluation Questionnaire (Leary, 1983); **BSQ-34** = Body Shape Questionnaire-34 (Probst, Pieters, & Vanderlinden, 2008); **CATS** = Child Abuse and Trauma Scale (Saunders & Becker-Lausen, 1995); **CES-D** = Centre for Epidemiological Studies for Depression (Weissman et al., 1997); **CTI** = Childhood Trauma Interview (Bernstein et al., 1994); **CTQ** = Childhood Trauma Questionnaire (Bernstein et al., 1994); **CTQ-SF** = Childhood Trauma Questionnaire-Short Form (Bernstein et al., 2003); **DAPP-BQ** = Dimensional Assessment of Personality Pathology- Basic Questionnaire (Livesley et al., 1992); **DEERS** = Difficulties in Emotion Regulation Scale (Grazt & Roemer, 2004); **DES-II** = Dissociative Experiences Scale (Carlson & Putnam, 1993); **DSM-IV** = Diagnostic and Statistical Manual of Mental Disorders (4th ed.); **DSM-IV-TR** = Diagnostic and Statistical Manual of Mental Disorders (4th ed.), Text Revision; **EAT-26** = Eating Attitudes Test (Garner et al., 1982); **ECR** = Experiences in Close Relationships Scale (Brennan et al., 1998); **EDE** = Eating Disorders Examination (Fairburn & Cooper, 1993); **EDE-Q 4** = Eating Disorder Examination Questionnaire 4 (Fairburn & Beglin 1994); **EDI** = Eating Disorder Inventory (Garner et al., 1983); **EDI-2** = Eating Disorder Inventory-2 (Garner, 1991); **EDI-3** = Eating Disorder Inventory-3 (Garner, 2004); **EDNOS** = Eating Disorder Not Otherwise Specified; **ESS** = Experience of Shame Scale (Andrews et al., 2002); **M** = Mean; **MMPI-2** = Minnesota Multiphasic Personality Inventory-2 (Butcher et al., 1989); **MOCI** = Maudsley Obsessional-Compulsive Inventory (Hodgson & Rachman, 1977); **RAAS** = Revised Adult Attachment Scale (Collins, 1996); **SCID-I** = Structured Clinical Interview for DSM-IV Axis I Disorders (First et al., 2007); **SCID-II** = The Structured Clinical Interview for DSM-IV Axis II Diagnoses (First et al., 1995); **SD** = Standard Deviation; **TSC-40** = Trauma Symptom Checklist-40 (Briere & Runtz, 1989); **YSQ** = Young's Schema Questionnaire (Young, 1999)



## Quality Assessment

Based on the use of the quality assessment tool, broad themes regarding quality of the included studies will be explored in this section. A table containing the full quality assessment for each study can be found in Appendix C. No studies were excluded from the analysis based on the quality assessment in order to present an accurate review of the available literature concerning the mediating variables between childhood maltreatment and eating disorders. However, the quality of the studies was somewhat variable, and this should be acknowledged when interpreting the results of the review. Some points of note following the quality assessment are described below.

**Measures.** Most studies used validated self-report measures. However, some measures used had lower levels of validity. Two studies (Craycraft, 2011; Vrabel et al., 2010) used medical records to assess a history of maltreatment, which is dependent on both a disclosure being made to medical staff and this being recorded accurately. This may not have captured all people with a history of childhood maltreatment. In addition, some studies used isolated subscales of validated self-report measures to assess childhood maltreatment, eating disorder behaviours, and mediating variables (Craycraft, 2011; Groleau et al., 2012; Steiger et al., 2011; Sweetingham & Waller, 2008). Determining the validity of a subscale from a larger measure is difficult which makes assessing the quality of such measures challenging.

**Sample Size and Power.** Only one study (Kong & Bernstein, 2009) commented on sample size and conducted a power analysis. It is therefore unclear to what extent the remaining studies could potentially be underpowered, which is of particular significance for studies reporting null findings (Craycraft, 2011; Groleau et al., 2012; Hewett, 2014; Steiger et al., 2011; Sweetingham & Waller, 2008; Vrabel et al., 2010).

**Mediation.** When considering the studies against the criteria for mediation proposed by Kazdin (2007), there are considerable limitations. There are a wide range of known consequences of childhood maltreatment, and combined with the multitude of eating disorder models, the studies all included mediators which met the plausibility criteria. However, mostly cross-sectional designs were used which means the timeline criteria could not be met by most studies as they did not include multiple time points. In addition, whilst childhood maltreatment as an independent variable has an inherent timeline quality to it (as it is historic), the criteria outlined by Kazdin (2007) require the mediation variable to be established prior to the dependent variable. As recruitment for all studies took place in eating disorder treatment settings, recruitment therefore occurred based on the presence of the dependent variable. This means that even studies that took

repeated measures cannot meet Kazdin's timeline criteria. Additionally, of the two studies which had follow up data available, only one (Vrabel et al., 2010) had a substantial amount available. None of the studies met the gradient or experimental manipulation criteria, as there was no measure of dose-response with any mediators, and manipulation of any of the variables in this research area would be unethical. Consistency and specificity were poor due to the range of mediators measured and the variation across studies. Whilst this is in part understandable due to the range of theoretical models and the range of maladaptive outcomes following child maltreatment, it is therefore difficult to determine which are the key mediational variables between childhood maltreatment and eating disorders.

Studies which used the causal steps approach outlined by Baron and Kenny (1986) and which included null findings include the possibility of type II errors (Craycraft, 2011; Groleau et al., 2012; Hewett, 2014; Kong & Bernstein, 2009; Sweetingham & Waller, 2008; Vrabel et al., 2010). One study (Everill et al., 1995) used ANCOVA, which is not commonly used as a measure of mediation. These methodological drawbacks could have important implications for the associations between independent variables, dependent variables, and mediators.

## **Study Results**

The studies reviewed cover a wide range of mediators. Results will be discussed in relation to theoretical models of eating disorders.

Firstly, a small number of mediators were explored which can be mapped onto cognitive-behavioural models of eating disorders, such as that posed by Fairburn (2003). These include perfectionism, body image disturbance, and obsessive-compulsive personality disorder (characterised by a high level of perfectionism and need for environmental control which significantly impacts upon a person's quality of life). However, none of these factors were shown to be significant mediators of the relationship between childhood maltreatment and eating disorders (Groleau et al., 2012; Hewett, 2014; Vrabel et al., 2010).

Some mediators focused upon emotional experiences, which are central to the model proposed by Fox and Power (2009). Some affective factors did not appear to mediate the relationship between childhood maltreatment and eating disorders. These factors included obsessive compulsion, social anxiety, and avoidant personality disorder (Kong & Bernstein, 2009; Sweetingham & Waller, 2008; Vrabel et al., 2010).

However, some affective factors were found to mediate the relationship between childhood maltreatment and eating disorders. Depression was evaluated as a mediator in

four of the studies reviewed, and all four suggested that depression mediated the relationship between childhood maltreatment and eating disorders (Groleau et al., 2012; Kong & Bernstein, 2009; Steiger et al., 2011; Waller et al., 2001). Additionally, shame was investigated by one study (Sweetingham & Waller, 2008), and was found to be a significant mediator.

Many studies explored mediators which map onto a cognitive-emotional-behavioural model as proposed by Corstorphine (2006). These mediators included beliefs around the self and others, beliefs about emotions, and emotion regulation. One study found ineffectiveness to mediate the relationship between childhood maltreatment and eating disorders (Groleau et al., 2012), while another did not (Craycraft, 2011).

Regarding relationships with others, both mistrust/abuse and abandonment schemas significantly mediated the relationship between childhood maltreatment and eating disorders (Waller et al., 2001). However, the findings for attachment patterns were mixed, with one study suggesting attachment was a mediating variable (Steiger et al., 2011), and another finding non-significant results (Hewett, 2014).

Finally, several factors were concerned with difficulties regulating emotions, and the findings for these mediators were mixed. Dissociation and emotional dysregulation were both significant mediators identified in the studies (Everill et al., 1995; Racine & Wildes, 2015; Waller et al., 2001). Affective instability had mixed findings, with one study suggesting it did mediate the relationship between childhood maltreatment and eating disorders (Groleau et al., 2012) while another did not (Steiger et al., 2011). Finally, borderline personality disorder, behavioural instability, and sensation seeking were all found to not be significant mediators (Steiger et al., 2011; Vrabell et al., 2010).

## **Discussion**

This review has examined the mediating factors between childhood maltreatment and eating disorders. There are several models which attempt to formulate the development and maintenance of eating disorders, and the findings of this review have important implications for these models and associated interventions.

Firstly, few studies had examined mediators which map onto the transdiagnostic cognitive-behavioural model of eating disorders (Fairburn et al., 2003). Those which were most related included perfectionism and body image disturbance. These factors were not found to be significant mediators of the relationship between childhood maltreatment and

eating disorders. These findings may suggest that, for the population of people with eating disorders who have experienced maltreatment, over-evaluation of shape and weight control may not be a central factor in the relationship between childhood maltreatment and eating disorders.

Depression and shame were found to be significant mediators. These findings are consistent with the affective model proposed by Fox and Power (2009), and appears to support evidence of negative affect being a crucial part of the onset and maintenance of eating disorders (Fox & Froom, 2009). In addition, shame as a significant mediator supports the use of a compassion-focused framework (Goss & Allan, 2010). Depression and shame may therefore need to be addressed as part of an eating disorder intervention. CBT is an evidence based intervention for depression (NICE, 2009), and future research could explore how elements of CBT for depression might be incorporated into existing eating disorder interventions. Shame is one of the core areas of focus in compassion focused therapy (Goss & Allan, 2010). Research suggests CFT-E is well-received by people with eating disorders (Steindl, Buchanan, Goss, & Allan, 2017), although the evidence-base is not large and CFT-E and other third-wave approaches are not currently implicated over CBT (Linardon, Fairburn, Fitzsimmons-Craft, Wilfley, & Brennan, 2017).

Finally, many studies examined mediators which mapped onto a cognitive-emotional-behavioural model (Corstorphine, 2006). Dissociation, emotional dysregulation, and abandonment and mistrust/abuse schemas were found to significantly mediate the relationship between childhood maltreatment and eating disorders. However, ineffectiveness, attachment patterns, and affective instability showed mixed results across studies. Borderline personality disorder, behavioural instability and sensation seeking were not found to be significant mediators. This inconsistency in findings across studies means the results are difficult to interpret with any certainty. Nevertheless, these findings could be understood through models proposed by Corstorphine (2006) and Waller et al. (2007), as well as compassion focused approaches (Goss & Allan, 2010), and the affective model proposed by Fox and Power (2009). These findings may indicate skills in emotion management and interpersonal relationships could be helpful as part of an intervention (Corstorphine, 2006). A common outcome of maltreatment is difficulty regulating emotions, and people with eating disorders have been found to have difficulties with emotion regulation (Corstorphine, Mountford, Tomlinson, Waller, & Meyer, 2007; D'Andrea et al., 2012). There is a suggestion that eating disorder symptoms may serve as an emotion regulation strategy (Corstorphine et al., 2007), and therefore may be an important target for intervention. However, as the findings for these mediators were mixed,

it is evident further research is needed to fully understand the relationship between childhood maltreatment and eating disorders.

### **Limitations of Included Studies**

In conducting this review, it is clear there are significant limitations to the evidence-base which must be acknowledged. Some of the mediators which have been explored in non-clinical populations have not been measured in a clinical population. These include PTSD, negative self-perception, thin ideal internalisation, drive for thinness, self-esteem, and alexithymia. Without exploring these potential mediators in a clinical population, it is difficult to determine whether these factors could also mediate the relationship between childhood maltreatment and clinical levels of eating disorders. Further research should explore whether all the factors identified as mediators of the relationship between maltreatment and disordered eating are applicable in a clinical population, as this could inform which models might be indicated as appropriate for use with this population.

The findings of this review need to be considered in the light of the breadth of mediators reviewed. Most mediators were only explored in one study, and three of the few mediators explored in multiple studies produced mixed findings. Overall, this means the reliability of most mediators reviewed has not been demonstrated, and further research is needed to understand which factors reliably mediate the relationship between childhood maltreatment and eating disorders.

In addition, to satisfactorily establish mediation, studies must demonstrate the temporal ordering of the different variables in order to support the proposed mediational model. Given all the studies in this review recruited at least part of their samples from services which offered interventions for eating disorders, none of the studies fully met this requirement and cannot truly establish causality. Temporal ordering would ideally be established using longitudinal studies in which the dependent variable is not present at the first point of measurement, but this may pose logistical difficulties in practise (e.g. difficulties with recruitment). Nevertheless, research designs need to include a strategy to ensure an independent variable occurred first, followed by the proposed mediator, and finally the dependent variable. Without such a strategy, the validity of the mediational model may be undermined. It is also crucial to ensure the statistical methods used are fit for purpose when measuring mediation. Most studies used a recognised and appropriate statistical approach to establish mediation. However, many used a causal steps approach,

which is a recognised strategy for establishing mediation but has been critiqued for resulting in a higher probability of type II errors. Future studies should carefully consider the statistical approach used to ensure it can establish mediation and minimise the possibility of type II errors.

### **Limitations of the Current Review**

One limitation of this review is that an inter-rater only reviewed a small proportion of abstracts, full texts, and included studies for data extraction and quality assessment. Despite the high rate of agreement between the two raters in the proportion of studies which were rated twice, ideally two raters would independently review all abstracts and studies to improve the reliability of the results.

A further limitation is the qualitative synthesis used in the study. This method does not control for author biases in comparison to quantitative review methods such as meta-analysis. However, the low number of studies eligible for review meant a meaningful meta-analysis of the findings was not possible.

### **Conclusion**

Overall, despite methodological limitations, the findings nevertheless suggest factors which map onto cognitive-emotional-behavioural and affective models may be important mediators of the relationship between childhood maltreatment and eating disorders. This has important clinical implications for how eating disorders may be formulated and intervened with clinically, and further research is needed to better establish which factors appear to be reliable mediators of this relationship. This can inform the ongoing development of clinically helpful ways of understanding and supporting people who have developed an eating disorder and have a history of maltreatment.

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# Service Improvement Project

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## **Team Formulation in Recovery Teams: Staff Perspectives and Recommendations for Team Managers and Psychologists**

Madeline Harris

M.G.Harris@bath.ac.uk

Department of Clinical Psychology

University of Bath

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### **Internal Supervisors**

Dr Emma Griffith | E.J.Griffith@bath.ac.uk

Dr Vuokko Wallace | V.Wallace@bath.ac.uk

### **External Supervisor**

Dr Nicci Earley | Nicci.Earley@nhs.net

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Clinical Psychology & Psychotherapy

This journal was chosen as it welcomes research on a breadth of clinically relevant issues and welcomes research which uses a qualitative methodology. Author guidelines can be found in Appendix D.

## Introduction

Formulation, in the context of clinical psychology, involves integrating a breadth of theoretical and clinical knowledge in order to create a tentative hypothesis to describe the difficulties service users may experience (DCP, 2011). A formulation should form the basis of any psychological intervention, and as such serves as the crucial link between theory and practice (Johnstone & Dallos, 2014). A formulation is considered effective if it is ultimately useful for the service user, and to support this aim practitioners need to be reflective and allow formulations to develop and change (DCP, 2011). Formulation is a core competency for clinical psychologists (Skinner & Toogood, 2010), however, utilising psychological thinking to inform interventions is not the sole domain of psychologists given the multi-disciplinary context of the NHS.

Team formulations, created by a multi-disciplinary team to construct a shared understanding of a service user's experiences, have attracted growing interest (Johnstone, 2014). The evidence base around team formulation is limited, especially concerning the effects of team formulation on service user outcomes (Johnstone, 2015). However, a small number of studies indicate team formulation is well received by staff (Christofides, Johnstone, & Musa, 2012; Hood, Johnstone, & Christofides, 2013). Using a shared team formulation to inform interventions can facilitate a more consistent and collaborative approach within a team, shifting team perspectives to a more holistic, psychosocial understanding of a person's difficulties (DCP, 2011; Johnstone, 2014).

Part of the role of a clinical psychologist is to take a lead role in the use of psychological formulation within teams (Skinner & Toogood, 2010), which includes providing training and supervision in team formulation (DCP, 2011). Evidence suggests that staff highly value training and subsequent ongoing support from psychologists to increase their confidence when using formulation (Hood et al., 2013). There are currently no consistent top-down recommendations regarding how formulation within teams can best be supported by psychologists, possibly due to how team formulation has developed in bottom-up fashion across different teams (Cole, Wood, & Spendelow, 2015).

Within the NHS, recovery teams are commissioned to work primarily with individuals who have been given diagnoses of complex mental health problems. National competency frameworks for psychological interventions within these teams recognise formulation as a competency which sits in the wider team (Roth & Pilling, 2008, 2013). British Psychological Society (BPS) guidelines for working within recovery teams include recommendations on team consultation and reflective practice, and working alongside

colleagues to promote psychological understanding (BPS, 2007). Support and leadership for formulation is therefore a key role for psychologists working in recovery teams, and evidence is required which highlights the most effective and efficient ways this can be achieved.

## **Project Context**

This project was carried out in two recovery teams in a locality within an NHS trust. Within the trust, multi-disciplinary care plans in recovery teams were required to be underpinned by psychological thinking. To address this need, all members of staff in both teams had been trained to use the 5 Ps model of formulation (Weerasekera, 1995). This training was provided by the Complex Psychological Interventions (CPI) team, which sits within the recovery teams. The 5 Ps model was selected as it provides an open and relatively atheoretical framework and, as such, was considered to be a good starting point for the formulation process (Dallos, Stedmon, & Johnstone, 2014). It is also thought to be accessible for multi-disciplinary staff with a variety of professional backgrounds (Priestman, Horner-Baggs, Yardley, & Cash, 2014).

To support formulation within the teams following this training, members of the CPI team facilitated ongoing reflective practice sessions. However, despite positive opinions expressed by staff, attendance at sessions was poor. Staff were also encouraged to informally consult members of the CPI team when they would like support in the formulation process. In practice, however, uptake for this offer was lower than expected.

## **Service Evaluation Questions**

The project aimed to answer the following questions:

1. Is a 5 Ps formulation being used by staff in their clinical work?
2. Are 5 Ps formulations useful to staff, and if so in what ways?
3. What supports staff to use a 5 Ps formulation?
4. What are the barriers for staff to using a 5 Ps formulation?



## Method

### Ethical Approval

Full ethical approval was obtained for this project from the University of Bath Ethics Committee (Reference Number 16-196) and service evaluation approval was given by the Research and Development department of the NHS trust in which the project was conducted.

### Participants

All recovery team staff in the two teams who had attended the 5 Ps training were invited to participate, excluding the CPI team, team managers, and administration staff.

### Design

The project used a mixed methods cross-sectional design, incorporating both quantitative and qualitative approaches. Quantitative methods were used to answer the first project question, and qualitative methods were used to answer the remaining questions.

### Quantitative Methodology

**Materials.** A questionnaire to gather brief descriptive data was used to answer the first project question. The questionnaire was developed in collaboration with supervisors and team managers and was piloted with two members of staff who were not eligible to participate as they had not yet attended the 5 Ps training. It was designed to be quick to complete to maximise return rates, taking no longer than ten minutes. A copy of the questionnaire can be found in Appendix E.

**Procedure.** Voluntary sampling was used. The questionnaire was distributed to all eligible potential participants (n=26) via email. The email contained information about the project and a link to the questionnaire, hosted by an online survey platform. Potential participants could volunteer to take part by clicking on the link. Full participant information was given and consent obtained via the survey platform. Potential participants were unable to access the questionnaire without first providing their consent to participate. Upon questionnaire completion, participants were thanked and debriefing information was given via the online survey tool. Two additional reminder prompts were sent via email to all eligible participants prior to analysis, in order to maximise participant numbers.

**Analysis.** Descriptive statistics were collated using the results of the questionnaire.

### **Qualitative Methodology**

Two focus groups were used to answer the remaining project questions. Focus groups were used to allow for both personal and group views to be captured and for rich data on these to be acquired. Focus groups were also used as they were felt to be a more efficient use of staff and researcher time.

**Materials.** A semi-structured interview schedule was used with the focus groups. The schedule was developed in collaboration with supervisors and reviewed by the two members of staff who piloted the questionnaire. The schedule was developed with the aim of collecting rich data to facilitate qualitative analysis. A copy of the prompts used can be found in Appendix F.

**Procedure.** All eligible participants (n=26) were invited via email to attend a focus group with others in their team, and voluntary sampling was used. A focus group was run for each of the two recovery teams. People who responded to the invitation were given participant information sheets and consent forms, which were read and signed prior to the focus group. Six people attended one of the focus groups, and ten people attended the other. The focus groups were 45-60 minutes in length and were facilitated by the lead author. The focus groups were audio recorded. At the end, participants were thanked and were given debriefing information verbally and via written debriefing sheets.

**Analysis.** The data was analysed using thematic analysis. This method was chosen as it is not bound to any theoretical framework and has been identified as an approach suited to informing policy development, which suits the service evaluation purpose of the project (Braun & Clarke, 2006). The analysis was completed in line with guidance outlined by Braun and Clarke (2006). The analysis considered a rich description of the whole data set and themes at the semantic level and adopted an inductive and essentialist approach.

Immersion in the data involved verbatim transcription of the audio recordings by the lead author, and multiple readings of the data. Initial codes were generated and the data was coded using the qualitative analysis software 'NVivo' (version 11). The initial codes and the number of data constituting each code can be found in Table 1. Pieces of data could be coded multiple times as needed, provided they were perceived to fit with each code. Themes were then tentatively created based on the codes and reviewed extensively, with some initial themes removed and others restructured. Review occurred both at the

level of the coded data extracts and at the thematic level in the context of the entire data set. The themes were then defined and named.

The lead author, who conducted the data analysis, had pre-existing knowledge of both teams and this had the potential to shape the interpretation of the data. To attempt to balance this bias, two strategies were employed. Firstly, a draft of the initial theme definitions, accompanied by examples of data extracts which typified each theme, was emailed to the focus group participants to receive their feedback on whether the analysis adequately captured their perspectives.

The second strategy involved an independent researcher, who separately grouped all the initial codes into the final themes based on the theme definitions and discussed any discrepancies with the lead author.

Table 1.

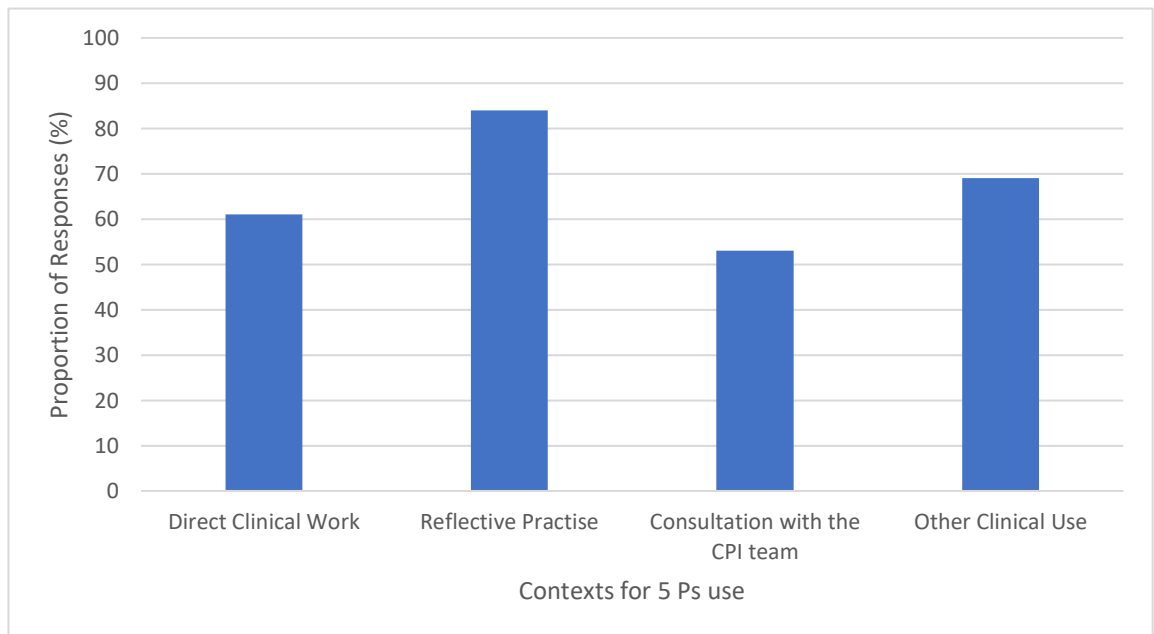
*Initial codes and frequency of data constituting each code.*

<b>Code</b>	<b>Data</b>
5 Ps - frequency of use	9
5 Ps - advantages	12
5 Ps - disadvantages	11
Alternatives to 5 Ps	11
Assessments	7
Dissemination	3
Effect on clients	6
Formulaic/mandatory use	3
Formulations	16
Interventions	7
MDT advantages	14
MDT disadvantages	2
Medical model	3
Practical constraints	16
Psychology referrals	2
Psychologists domain	2
Staff morale	12
[Team 1] combined meeting	4
[Team 1] separate meeting	4
Sympathy/compassion	7
Team formulation	24
Training	6
Triage and crisis	10

## Results

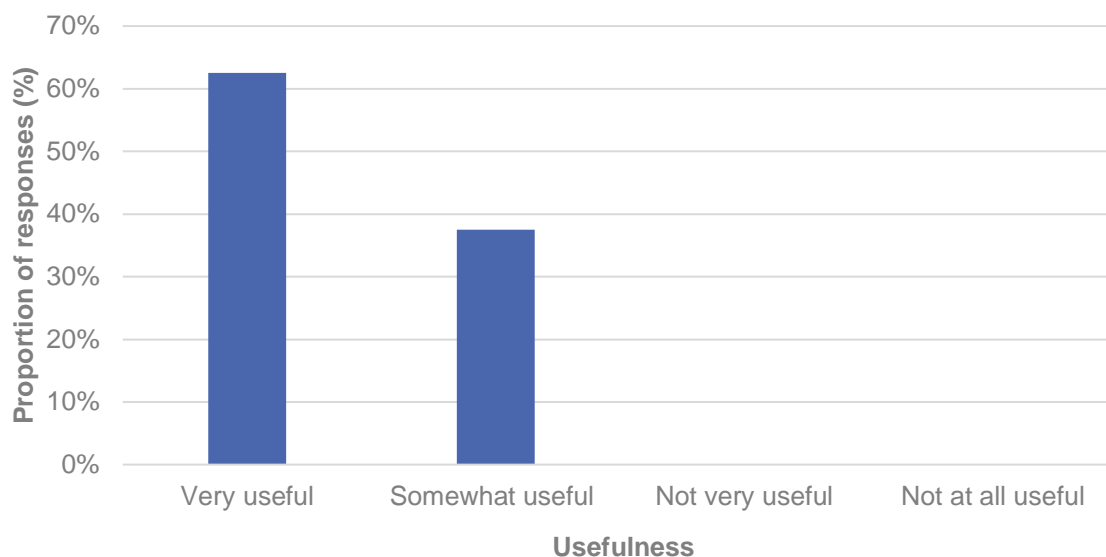
### Descriptive Statistics

The first project question, to provide an overview of the use of the 5 Ps model, was addressed by the questionnaire. The questionnaire was completed by 13 participants, and the results are summarised using descriptive statistics. Responses were received from nurses, support workers, social workers, therapists, and vocational workers. Eight participants were based in one of the teams, and five in the other. The proportion of respondents who used the 5 Ps model in different contexts is presented in Figure 1.



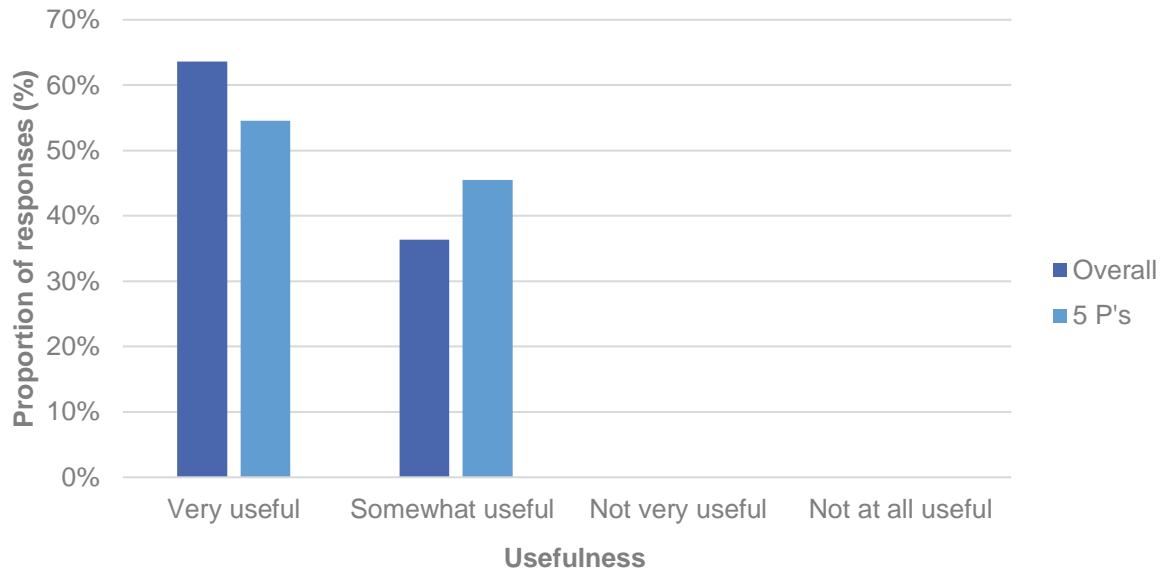
*Figure 1.* Proportion of respondents who used the 5 Ps model in different clinical contexts.

**Direct clinical work.** Eight of the 13 participants had used the 5 Ps in direct clinical work. Participants' views on the usefulness of the 5 Ps model in direct clinical work are shown in Figure 2.



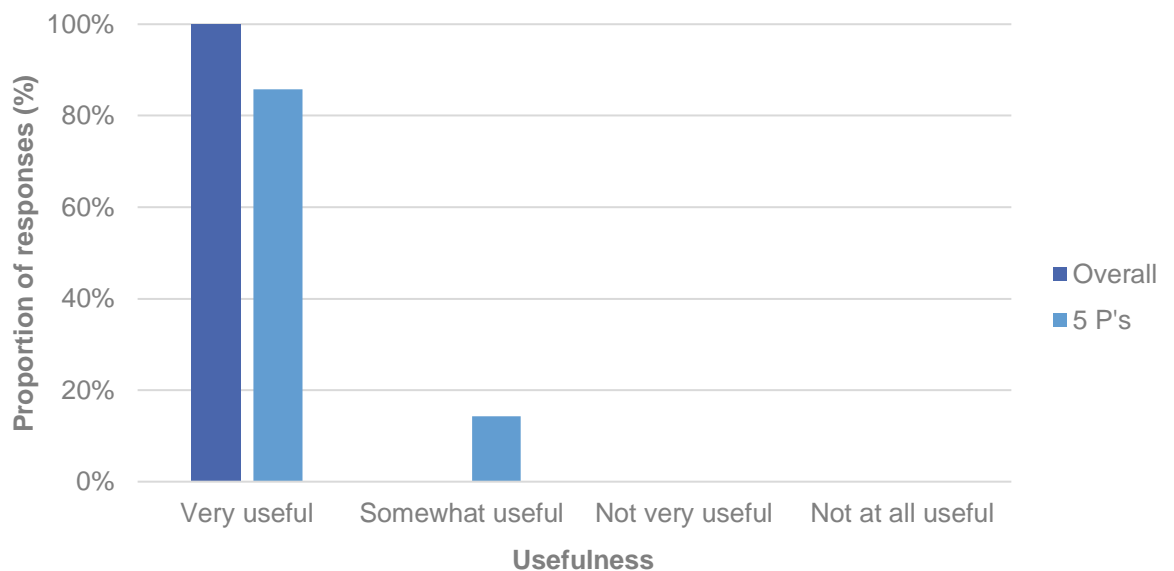
*Figure 2.* Graph depicting usefulness of 5 Ps in direct clinical work.

**Reflective practise.** Eleven of the 13 participants had attended reflective practise sessions at least once, and five had attended five or more sessions. Of those who had attended a reflective practise session, all had used the 5 Ps model in this context. Participants' views on the usefulness of reflective practise, and the 5 Ps model in this context, are shown in Figure 3.



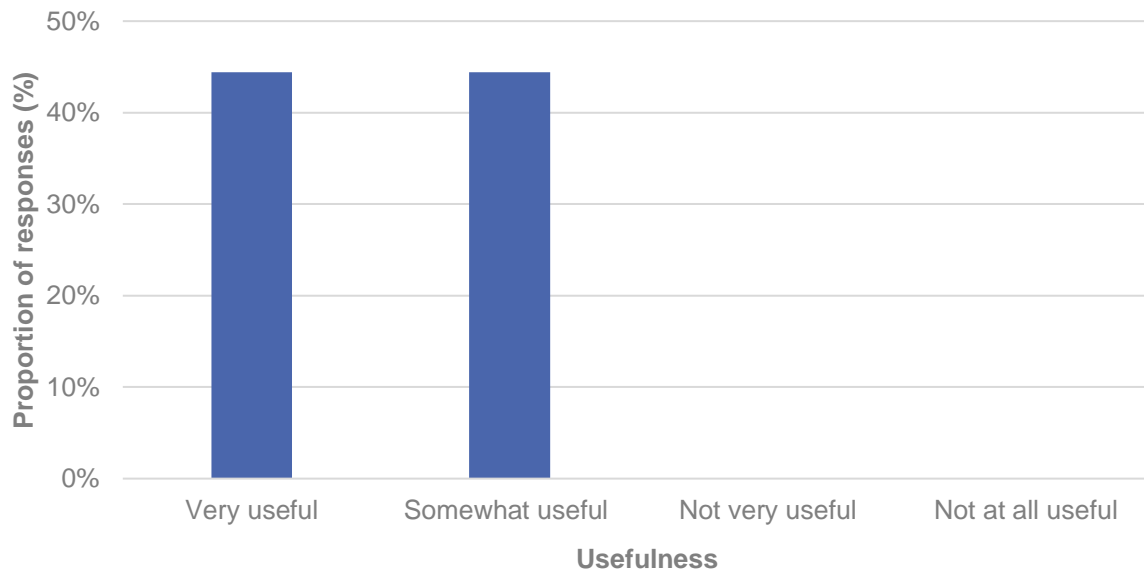
*Figure 3.* Graph depicting usefulness of reflective practise overall (left bars), and the 5 Ps when used in reflective practise (right bars).

**Consultation with the CPI team.** All participants had consulted with the CPI team about their clinical work outside of reflective practise sessions. Seven of the 13 participants had used the 5 Ps framework when consulting with the CPI team. Participants' views on the usefulness of consulting with the CPI team about their clinical work, and the use of the 5 Ps model in this context, are shown in Figure 4.



*Figure 4.* Usefulness of consultation with the CPI team overall (left bars) and when the 5 Ps is used in this context (right bars).

**Other clinical use.** Nine participants had used the 5 Ps model in other ways than those already described. These included for assessment and formulation purposes, and inclusion with a referral for psychological intervention. Participants' views on the usefulness of the 5 Ps model in other contexts are shown in Figure 5.



*Figure 5.* Graph depicting usefulness of using the 5 Ps in other contexts. nb. Answers do not total 100% due to missing data.

## Thematic Analysis

The focus groups, designed to address the remaining project questions concerning how 5 Ps formulations are useful, and what staff find can support them or act as barriers when using the 5 Ps framework, were analysed using thematic analysis.

**Strategies to address bias.** The draft themes were shared with the participants, with an invitation to respond with any thoughts and suggestions. No participants responded with comments suggesting changes to the analysis.

An independent researcher separately coded all the data extracts and coded them based on the final thematic structure. Following an in-depth discussion, the initial inter-rater agreement rate was 90.43%.

Whilst there was unfortunately no feedback given by the focus group participants, the high rate of agreement with an independent researcher does allow the possibility of increased confidence in the analysis.

**Thematic Map.** The thematic map is shown in Figure 5, and the themes and sub-themes are explored in depth in the subsequent sections of the analysis.

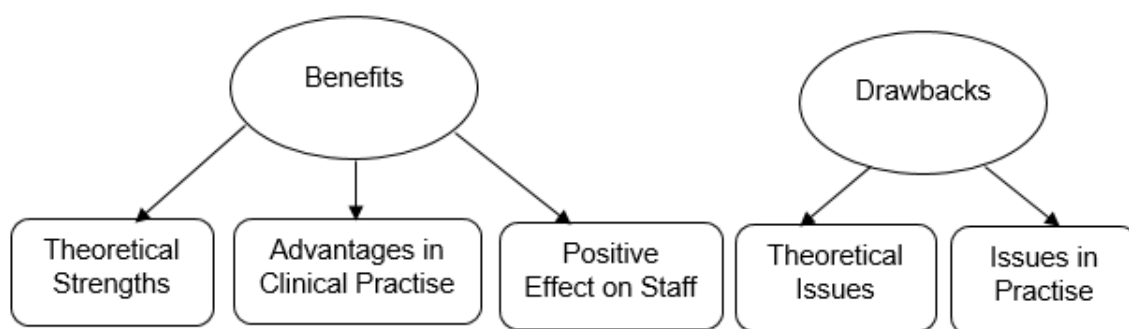


Figure 5. Thematic map.

**1. Benefits.** This theme encompasses the perceived advantages of the 5 Ps model. The theme is made up of three sub-themes.

**1.1. Theoretical Strengths.** This sub-theme captures views on the 5 Ps model itself. Some participants spoke favourably about the simplicity of the model and the structure it provides.

*“It is, it is a good structure” (FG2: 295)*

*“It’s not like a massively complex model” (FG1: 39)*

Participants also spoke about theoretical issues, including the model holding a relatively atheoretical stance allowing multiple professional perspectives to be incorporated. Some participants considered the model to provide a more balanced approach when contrasted with comparatively hierarchical models.

*“But what the 5 Ps does balance is the traditional hierarchy where we look to a medic for consultation and for understanding what’s happening, because they don’t have the answers, none of us do, but this is a way of kind of...generating [...] helpful questions” (FG1: 255-259)*

**1.2. Advantages in Clinical Practise.** The advantages in clinical practise sub-theme explores the positive effects the 5 Ps models had upon the participants’ work. Participants described how the model brought structure to many areas of their work, including assessment, formulation, and intervention.



*“You can see them more as an individual and what might be helpful to them rather than just kinda thinking ‘I’ll do the same with them as I did with someone else’.”*  
(FG2: 185-186)

*“Sometimes I find I’m going down a blind alley, I need to pull back, and I think it’s there where the 5 Ps can be quite useful”* (FG2: 202-204)

There was discussion of how the 5 Ps framework facilitates the sharing of information, with the benefits of this during crisis or triage situations and when sharing with external care agencies being highlighted.

*“Then you speak to them on triage, so it’s a good way of getting to know the background about people”* (FG2: 137-138)

*“Then when there was problems at the home we say ‘We sent you all the psychological formulation, read through it, we’ve got a really detailed care plan’ and then two days later they phone back and say ‘Yeah he’s calmed down now’”*  
(FG1: 428-431)

This sub-theme also captures participants’ thoughts on how using the 5 Ps allowed them to be more reflective during their work, and would support them when making sense of people’s experiences.

*“When you’ve heard why they are like they are, you feel much more sympathetic than if they’re just the person who phones up and never seems to be solvable”*  
(FG2: 166-168)

The ideas explored link with the “theoretical benefits” sub-theme. The benefits of the theoretical attributes of the model became apparent when participants described the impact of using the model on clinical practise.

**1.3. Positive Effect on Staff.** This sub-theme explores the personal and systemic impact from use of the model. Participants described how using the model encouraged sympathy and compassion for the people they work with, and some observed how this had a reciprocal effect on their therapeutic relationship and service user outcomes.

*“It’s really interesting because it helps with compassion fatigue, doesn’t it?”* (FG2: 175)

*“And she has felt more listened to, hasn’t she?”* (FG1:618)

There was also discussion concerning how use of the model in a team formulation context would contribute to a sense of feeling supported by the team.

*“I think [psychologist]’s sessions are more really good supportive, emotional, kind of holding each other in difficult problems” (FG1: 595-597)*

The ideas here link with the other “benefits” sub-themes. In particular, the enhanced understanding of service users initially described in the “benefits in clinical practise” sub-theme interacts with the sympathy and compassion generated in staff by use of the model. In turn, participants then described how this sympathy and compassion would have a valuable effect in clinical practise, including on their relationship with service users. Discussion also acknowledged the experience of using the model in team reflective practise, which would impact upon the team’s emotional experience of their clinical work.

**2. Drawbacks.** This theme explores the difficulties participants encountered when using the model. This theme consists of two sub-themes.

**2.1. Theoretical Issues.** This sub-theme encompasses the downsides participants perceived with the model itself. Some drawbacks were superficial, such as difficulties remembering all the P’s.

*“Thinking ‘Oh I can’t remember what the next P is’ is not massively helpful.”*  
(FG2: 47)

Others were more fundamental to the model itself. Some participants voiced opinions that using the model may not add anything extra to their existing practise, or the benefits of using the model may not be due to the model itself, but instead to how it is used. Some participants highlighted the similarities between the 5 Ps model and other models they had been trained in, and expressed a preference for the model they were already using.

*“Taking a personal history has always been part of the medical psychiatric assessment and I just never shifted to calling it 5 Ps even though it’s virtually the same thing” (FG2: 39-42)*

*“It’s not the model, it’s the time, and the space, the compassion and the supervision, there’s lots of other things that make up a good model, a good understanding and good intervention.” (FG1: 493-496)*

The ideas explored here do not necessarily contradict the advantages of the model discussed in the “benefits” theme. However, key questions raised in this sub-theme concern whether the advantages of the 5 Ps model are unique or inherently due to the model itself. Participants discussed different models they use in practise, and did not appear to feel the 5 Ps offered any additional benefits. Discussion also began to explore contextual factors which may affect success when using the model, such as time, active listening, and compassion. These factors continued to be explored in the final sub-theme.

**2.2. Issues in Practise.** This final sub-theme encapsulates problems encountered in practise which limit the effective use of the 5 Ps model. Some participants described practical constraints, such as limited time and the additional paperwork generated by use of the model, which means they are unable to use it as often as they would hope.

*“There’s so many more things we’ve got to do [...] and I think it does get missed.”*  
(FG1: 512-513)

A few participants commented on lack of practise or experience with using the model – either their own or of others in their team – which inhibited confidence and continued use of the model.

*“There were people in the meeting who had done the training but had never used it since [...] so it seemed like they weren’t quite getting out what the rest of us were hoping to”* (FG1: 137-139)

Participants also described instances in which the model had been used inappropriately, either by other services or by their own teams, and reflected on why this might have happened and the difficulties this caused.

*“I read one of their [another service’s] things the other day and they’d used the 5 Ps but in the most brief and [...] tick box way [...] and it was just as meaningless as anything else we do”* (FG1: 463-465)

Finally, some participants who raised difficulties using the model within their own team context shared their own hopes for the use of the model in the future.

*“But the team meeting discussions [...] it’s not going to be supportive supervision [...]. The dynamics are too...untested, really, to feel safe in that way”* (FG1: 550-553)

*“I think that will evolve with time as we all get used to it, as we get used to each other, and as long as we don’t fall into that kind of hierarchical thing [...] I think we have to be really mindful of it.” (FG1: 598-601)*

*“It’s being able to go to the one supervision, one really good, really accessible supervision, with or without the 5 Ps...” (FG1: 582-583)*

Some of the ideas discussed in this sub-theme contrast with the emotional benefits of supervision discussed in the “positive effect on staff” sub-theme. The disparity between the situations described in these two themes is stark, and a key component of the difficult situations described here was the presence of negative emotions, including feeling unsupported, irritated, and upset. These experiences are vastly different to the experiences of support described in the “benefits” theme.

The instances of the model being used inappropriately expands on the idea first explored in the “theoretical issues” section, namely that the benefits which can come from use of the 5 Ps may be due more to contextual factors rather than the model itself. The examples discussed in this sub-theme highlight how the model can be used poorly - for example, in a tick box manner, or by sessions being unfocused – and how this was experienced as unhelpful. These examples appear to support the idea there are conditions which need to be met before the model can be used effectively, such as adequate resources, training, compassion, and use of good listening skills.

Participants’ discussion of how they might like these difficulties to be reconciled allows for valuable insight into their priorities when using a model such as the 5 Ps. The model seemed to serve a valuable role within the team, especially in contexts in which other models are not already present, such as team working situations or when practitioners do not have an alternative preferred model. Participants appeared to appreciate the emotional support and space to think as a team in a group supervision context in which the 5 Ps is used. Overall, participants appeared to prioritise this above a preference for any model.

The two focus groups came from different teams within the same locality, which had different cultures around team use of the 5 Ps. One team had a well-established whole MDT reflective practise, which participants described as supportive. The other had a smaller reflective practise group which used the model, and a larger separate MDT meeting. Participants from this team described experiencing the small reflective practise as supportive, however a new attempt to introduce the 5 Ps to the MDT meeting appeared to be less successful. Participants differed in their ideas about whether this could work and

become a more supportive experience with time. One participant felt the group may be too big to ever be as supportive as the smaller group, whereas another hoped it could become a more positive experience if the wider team was to be given an additional opportunity to use the model and to formulate in practise.

## **Discussion**

This project aimed to answer four questions, the first of which was to gather information on how staff in the recovery teams were using the 5 Ps model. The results of the project suggest the 5 Ps model was used in a variety of ways by the two teams: in direct clinical work and to inform clinical thinking, in consultation with the CPI team, and in group reflective practise. It was most consistently used in a reflective practise context and least consistently used in informal consultation with the CPI team. Nevertheless, all these experiences with the model were described as useful to some degree by those who participated in the questionnaire.

The second project question was concerned with how staff found the 5 Ps model to be useful. Both teams described how the model was useful across a variety of contexts, including assessment, formulation, intervention planning, and communicating with other professionals. Participants described the model as easy to understand and accessible to a variety of professionals. Reflective practise sessions which used the model to structure team formulation were very well received, and participants described how these provided emotional support and countered “compassion fatigue”, which had a positive impact both upon staff morale and relationships with service users.

The third project question aimed to explore what factors support staff to use a 5 Ps formulation. Several participants referred to the need to be adequately resourced to use the model effectively, which included sufficient time and a manageable workload. Some participants acknowledged the emotional support provided by reflective practise sessions facilitated by members of the CPI team who are knowledgeable about the model. This in turn supported them to use the model effectively and to feel emotionally supported and “safe” in doing so.

The final project question was designed to elicit the barriers which limit use of the 5 Ps model in the teams. Many participants described a lack of time and a large workload, which restrict the use of the model in both clinical work and in attending reflective practise sessions. Some participants described a lack of clarity regarding the use of the 5 Ps and

preferences for models they already used. Others were unsure how the 5 Ps framework could be useful if other models were being used. A small number of participants highlighted how use of the model in a team context was experienced as more difficult if some staff present were not trained in use of the model.

Overall, the 5 Ps model was well received and served the purpose of supporting psychological formulation in the two recovery teams to support the care of service users. Use of the model within the team appeared to support staff to be more reflective and holistic in their approach, which is important for effective formulation (DCP, 2011; Johnstone, 2014), and indicates the model, despite some drawbacks, appears to be fit for the purpose of supporting staff to use psychological thinking in their work. The project has also highlighted areas for service improvement, and the results can offer guidance for the psychologists within the team on how they can best support the rest of the team with formulation, as outlined by the BPS (BPS, 2007).

## Service Recommendations

Based on the findings of this project, a number of recommendations to the service for future practise are outlined in Table 2.

Table 2.

*Service recommendations.*

<b>Existing practise to be continued</b>	
<b>1. Continue use of the 5 Ps model</b>	The 5 Ps model is already embedded onto the notes system used by the service, and participants provided many reasons why the model is useful in their clinical practise.
<b>2. Continue facilitated use of the 5 Ps model</b>	Participants described both the clinical and emotional support provided by facilitated sessions based on the model, and were keen for these to continue.
<b>Recommended changes</b>	
<b>3. Ensure all staff are trained in use of the 5 Ps model</b>	Participants highlighted how, if some staff are not trained in the use of the model, this can disrupt the team formulation process for trained staff.
<b>4. Ensure protected time to use the 5 Ps model, to include an</b>	Participants reported feeling unable to choose whether to attend reflective practise sessions or catch up on work because their workload is too large to manage both.

<b>adjustment to workload</b>	Participants explained the model only works if time and effort are dedicated to it, so staff need to be adequately resourced to use the model effectively.
<b>5. Ensure a greater number of skilled reflective practise facilitators are available</b>	Staff highly valued having facilitated sessions. At the time of evaluation, the facilitation of these sessions was consistently implemented by a small proportion of the CPI team. To ensure the continuation of team formulation in the event of staff absence and turnover, a greater number of facilitators skilled in using the 5 Ps is required. This role does not need to be limited to the CPI team.
<b>6. Support staff to use the 5 Ps model as a framework to complement existing models staff may already use</b>	<p>This would support staff to use the model without feeling they need to choose between the 5 Ps and other models or feel using the 5 Ps is “reinventing the wheel”.</p> <p>This could be initially explored in reflective practise sessions to gauge staff views on preferences as to what this support might look like.</p>
<b>Further evaluation</b>	
<b>7. Plan further service evaluation exploring the impact of the 5 Ps on service user experiences and outcomes</b>	Findings from further service evaluation in these areas would further inform how teams can support service users. This information would also be crucial to shape the implementation of team formulation training across the trust.
<b>8. Implement a service evaluation of use of the 5 Ps on the notes system</b>	<p>Evaluation of both the richness and quantity of 5 Ps formulations completed for people on recovery team caseloads would serve several functions:</p> <ul style="list-style-type: none"> <li>• Long term evaluation of the training provided via pre and post measures</li> <li>• Inform outstanding training needs, by identifying areas of consistent difficulty in formulations</li> <li>• Highlight staff who may not be using the model consistently. If staff were willing, this could potentially open up conversations on their views and outstanding</li> </ul>

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training needs, which were unlikely to be captured by the recruitment strategy used in this project.

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### **Service Response**

The results of the analysis were fed back via a presentation to the team and other psychologists in the trust who had an interest in developing formulation in their own teams. The results were well received and led to fruitful discussion and reflections on possible next steps, both within the recovery teams who participated and other teams within the trust. The results provided confirmation for the CPI team and the team managers that formulation is well received by staff and there is a clear rationale to continue to use the 5 Ps model, and that staff need to be appropriately supported to use the model successfully.

### **Implementation of Recommendations**

Since the project was carried out, more of the CPI team are now facilitating reflective practise using a consistent approach. Future service evaluation is planned, particularly to develop an understanding of service user experiences of formulation. Recovery team staff in the locality are now taking part in a care plan pilot, and they opted to use care plans which incorporate the 5 Ps, further confirming the popularity of the model. This pilot may also provide detailed information on realistic ways staff can be supported to use the model, given the current context of limited resources in the NHS. The model is now being piloted in other specialties within the trust, such as learning disabilities and older adults, and the results of this project are informing the training provided.

### **Limitations of the project**

There are limitations with the methodology which require consideration. Firstly, the voluntary sampling method used carries a risk of voluntary response bias. Those who may hold predominantly negative views about the 5 Ps model, or are indifferent towards it, are less likely to have had their perspectives captured by the methodology used.

The social context of focus groups may have meant some participants felt reluctant to honestly express their perspective or challenge a dominant view. This is particularly pertinent for the larger focus group, which involved participants at different levels of the team hierarchy.

The lead author and regional supervisor were known to the participants. Whilst the lead author, who conducted the focus groups, was no longer a member of either recovery team; it is possible participants may have given different responses if the researcher and



supervisor were not known to them as colleagues. In addition, as the lead author conducted the analysis, their pre-existing knowledge of the teams will have shaped the interpretation of the data. Steps were taken to address this, including an independent researcher separately coding the data, sharing tentative themes with participants, and close collaboration with supervisors during the analysis process; however, the absence of feedback from the participants increase the likelihood that the lead author's perspective shaped the final analysis.

## Conclusions

This project explored recovery team experiences of using the 5 Ps model as a framework for team formulation. When taken together, the findings suggest the 5 Ps model was experienced as useful across numerous clinical contexts and allowed teams to use formulation with service users. The framework was accessible to those without prior professional training, as well as those who had a professional background with its own models; however, some participants who used other models experienced difficulty integrating the 5 Ps into their existing practise. Overall, the model supported recovery teams and CPI staff within these teams to use psychological formulation. Further evaluation is necessary to assess the impact of any recommended changes, and to understand the effect of team formulation and use of the 5 Ps upon service users.

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# Main Research Paper

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## **Parental Illness Perceptions in Type 1 Diabetes and JIA**

Madeline Harris

M.G.Harris@bath.ac.uk

Department of Clinical Psychology

University of Bath

May 2018

### **Internal Supervisors**

Dr Cara Davis | C.Davis@bath.ac.uk

Professor Paul Salkovskis | Paul.Salkovskis@hmc.ox.ac.uk

### **External Supervisors**

Dr Claire Semple | Claire.Semple@UHBristol.nhs.uk

Dr Sangeeta Sawlani-Ramos | Sangeeta.SawlaniRamos@UHBristol.nhs.uk

### **Word count**

6031

### **Intended Journal for Submission**

Journal of Pediatric Psychology

This journal was chosen as the editors welcome submissions of papers regarding young people and their systems in relation to paediatric health. The journal encourages work relating to both research and clinical practise. Author guidelines can be found in Appendix G.

## Introduction

One in seven children and young people (CYP) in the UK have a long-term health condition (LTC) which has no cure and requires ongoing management (Hagell, Coleman, & Brooks, 2015). Poor adherence to ongoing treatments in LTCs is common, and this can have a substantial impact upon the effectiveness of treatments (WHO, 2003).

Psychological models which aim to understand attitudes towards healthcare and treatments are therefore of substantial interest in order to promote effective healthcare. There are several psychological models which have been proposed to explain why some people may struggle to engage with treatments, which draw on different theories. Behavioural models suggest the use of environmental antecedents and consequences will shape healthcare behaviours. Communication based models focus instead on improving communication between healthcare systems and service users and propose this will facilitate positive healthcare behaviours. Cognitive models, such as the health belief model and the theory of planned behaviour, focus on beliefs, attitudes and expectations for the future and how these impact on healthcare behaviours (for a fuller overview of these models, see Munro, Lewin, Swart & Volmink (2007)).

One of the most popular models used over several decades is known by many names, including the ‘Common Sense Model’ (CSM; Leventhal, Meyer, & Nerenz, 1980). The CSM proposes that both cognitive and emotional components of illness perceptions can affect how people react to LTCs. The model suggests there are five dimensions to the cognitive component of illness perceptions:

1. Identity: the perceived symptoms of the illness
2. Cause: attributions regarding the cause of the illness
3. Consequences: perceptions of the wider effects of the illness, which can include physiological, psychological, and social components
4. Timeline: beliefs concerning the anticipated duration of the condition
5. Control/Cure: perceptions of curability or controllability of the condition via treatments and self-management

These dimensions relate to individuals’ perceptions of the condition, which may differ from those held by healthcare professionals. Illness perceptions are thought to inform a person’s coping strategies and their appraisals regarding the success of these strategies, which in turn can then update illness perceptions (see Figure 1).

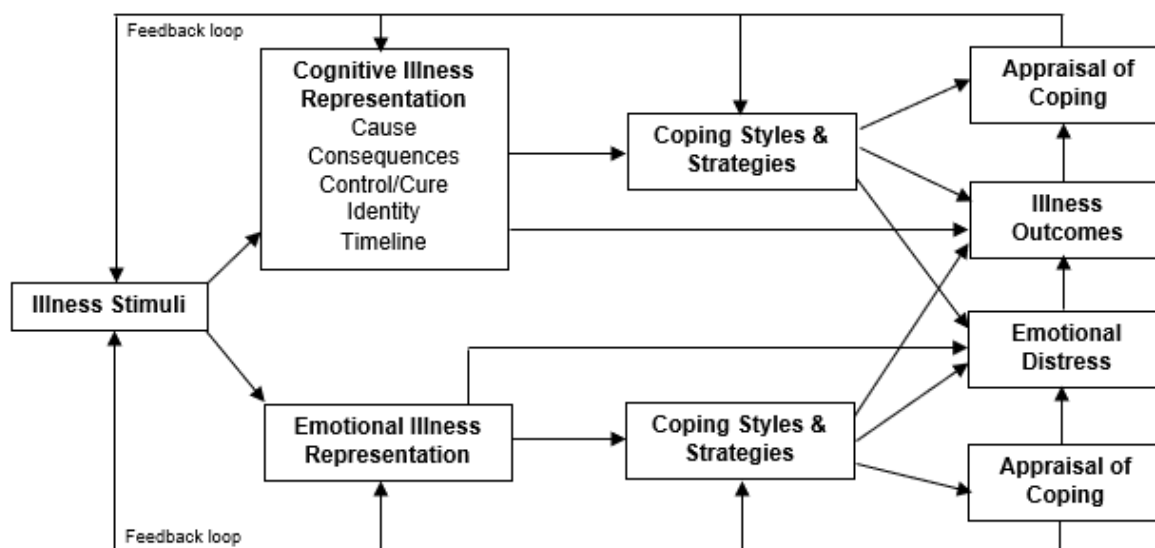


Figure 1. The CSM. Figure adapted from Hagger & Orbell (2003).

The CSM can be used to understand how health perceptions and coping styles influence outcomes, and a meta-analysis has confirmed predicted links between illness perceptions and coping styles in adults (Hagger & Orbell, 2003), and between illness perceptions and health management behaviours in CYP (Law, Tolgyesi, & Howard, 2014). One of the strengths of the CSM is that it recognises illness perceptions can be updated over time in response to experience, which is a potential mechanism for changing perceptions to lead to more helpful health behaviours. The model also acknowledges that perceptions may not necessarily match the medical perspective of a condition. This means the model may be useful to explain why a person could view their condition differently from their medical team. However, despite these strengths, the model has some drawbacks. Most of the evidence supporting the model is based upon cross-sectional studies, which means it is difficult to establish the causal role of illness perceptions as suggested by the model. Indeed, some research has suggested that illness perceptions may affect health outcomes independently of coping behaviours, which is contrary to the model (Hagger & Orbell, 2003). Similarly, a recent review has found that illness perceptions do not appear to influence health outcomes (Aujla et al., 2016), a finding which would also not be predicted by the model. In addition, despite the model demonstrating illness perceptions can be updated and changed, there is little detail offered regarding this process. This means the model provides limited guidance for appropriate interventions which could alter illness perceptions and promote positive health behaviours.

An additional substantial drawback of the CSM is that it neglects systemic factors (Law, Tolgyesi, & Howard, 2014). These factors are significant for everyone, but

especially so when considering the illness perceptions of CYP. Bandura's Social Cognitive Theory (1986) proposes people learn from observing others; this is particularly applicable in childhood where learning occurs via observation and parental influence over the child's environment. Furthermore, early life experiences influence schema development, so this learning persists in the form of cognitive structures through which a person interprets the world (Beck et al., 1979). On this theoretical basis, beliefs held by others could influence illness perceptions, particularly those of CYP. The importance of systemic working in paediatric health settings has been acknowledged in clinical practise (e.g. Fredman, Christie & Bear, 2007), but many adherence models such as the CSM fail to incorporate this as a significant factor.

Research has begun to explore illness perceptions of caregivers, which have been linked with outcomes for the person with the health condition, including their self-care (Gaston, Cottrell, & Fullen, 2012), their own illness perceptions (Karademas, 2013), quality of life outcomes (Terrasson, 2018) and familial management of the health condition (Årestedt, Benzein, & Persson, 2015). Perceptions vary within a family, with caregivers tending to hold more pessimistic illness beliefs than the person with the illness. Caregivers for adults with cancer, for example, held more negative illness beliefs than the person with the diagnosis. These perceptions were associated with negative adjustment in those with cancer, even when their own illness perceptions were controlled for (Olsen, Berg, & Wiebe, 2008; Richardson, Morton, & Broadbent, 2015). Additionally, dissimilar illness beliefs in a family are associated with health management complications (Heyduck et al., 2015). Differences in illness perceptions have also been observed between CYP and parents; parents can have more negative beliefs about symptoms and consequences of their child's type 1 diabetes (T1D) than their child (Gaston et al., 2012; Law, 2002). Research with CYP with juvenile idiopathic arthritis (JIA) suggests the difference between parental and CYP illness perceptions is greater when the child is older, when the illness has lasted longer and has affected more joints (Misterska et al., 2017). These findings indicate caregiver illness perceptions may differ from those held by the person with the condition, and these perceptions may also influence a person's adjustment and health outcomes. However, as the CSM does not incorporate systemic illness perceptions, there remains scope for further investigation of how these factors relate to each other and inform support for families.

As the knowledge base regarding familial illness perceptions is so limited, the present study is an initial pilot to explore the nature of parental illness perceptions across different health conditions, and how these might be affected by factors which have been

implicated as significant in the illness perceptions literature and broader psychological theory. The smaller scope of this study means the study focuses specifically upon the cognitive illness representations, and does not explore the other components of the CSM.

Perceptions of illnesses would reasonably be expected to vary dependent on the illness in question. Indeed, illness perceptions have even been shown to vary between health conditions which are relatively similar symptomatically (e.g. psoriatic and rheumatoid arthritis, Kotsis et al., 2012). The health behaviours which constitute effective LTC management can also vary dependent on the condition, and these differences have also been linked with variability in illness perceptions (Huston & Houk, 2011). Additional condition-specific factors, such as how life-threatening the condition is, have also been proposed to lead to differences in illness perceptions and responses to a condition. Research has shown substantial differences in illness perceptions and associated coping and outcomes in CYP and their parents who have cancer compared with those who have JIA (Graziano et al., 2016). This study explores the differences between illness perceptions of parents of CYP with two different LTCs: T1D and JIA. These two conditions were chosen because they are both autoimmune conditions with no known cure, are not life-limiting if managed well, but nevertheless require substantial input from CYP and parents to manage successfully. These conditions would therefore be interesting to explore as part of this initial pilot study aiming to understand the similarities and differences of parental illness perceptions between LTCs.

T1D is an autoimmune condition of unknown cause in which the pancreas does not produce insulin. Long term complications of T1D can include damage to the eyes, kidneys and nerves. Treatment involves injecting insulin several times per day and calculating insulin dosage based on blood tests and carbohydrates consumed. Currently people with T1D require lifelong treatment. Approximately 29,000 children have T1D in the UK (JDRF, n.d.; NICE, 2015). The gender split for T1D in CYP is approximately equal (Soltesz, Patterson, & Dahlquist, 2007). In contrast, JIA is characterised by painful swelling in the joints with no known cause and onset by age 16. There are different kinds of JIA, including oligoarthritis, enthesitis related arthritis (ERA), polyarthritis, psoriatic arthritis, systemic onset JIA, and undifferentiated arthritis. Treatment can include steroid injections into joints to reduce swelling, or medications which calm the immune response responsible for the swelling. Treatment aims to minimise potential complications, such as eye problems and joint damage, and to achieve symptom remission (Shoop-Worrall, Kearsley-Fleet, Thomson, Verstappen, & Hyrich, 2016). Twelve thousand CYP under 16

years have JIA in the UK, and approximately twice as many girls develop JIA than boys (Bailey, 2014; Kahn, 2013).

T1D and JIA are both autoimmune conditions of unknown cause, have no known cure, and require CYP and families to have ongoing involvement in condition management. However, differences between conditions may affect illness perceptions. Firstly, the differing symptom presentations may understandably affect the identity dimension of illness perceptions. Secondly, insulin therapy for T1D is the sole treatment option and is guaranteed to be effective when administered accurately. However, calculating the correct amount of insulin to administer several times a day can lead to substantial treatment burden. In contrast, people with JIA may be offered various effective interventions, but which offer less certainty of outcome than insulin. However, such interventions place fewer demands on CYP and families, and some may be entirely managed by healthcare professionals. These treatment differences may therefore have implications for the control dimension of illness perceptions. Finally, whilst potential long-term consequences of JIA can substantially affect quality of life, poorly managed T1D can be fatal. This may lead to differences in consequence perceptions.

Aside from objective illness factors such as those described above, there are several factors implicated in the wider literature which may affect illness perceptions. Firstly, illness perceptions are a form of cognition. Cognitive theory proposes that thoughts drive behaviours and emotions and these can then reinforce cognitions (Beck, 1976, 1987; Beck, Emery, & Greenberg, 1985), and research suggests mood and anxiety can be predictive of illness perceptions (Arat, Rassart, Moons, Luyck, Vandenberghe & Westhovens, 2018). Secondly, illness perceptions have been shown to vary in relation to time since diagnosis, including changes in expected illness duration and less perceived personal levels of control (Fischer et al., 2010). Therefore, mood, anxiety, and time since diagnosis are all variables which could influence illness perceptions independent of the LTC itself, and ideally should be controlled for when considering illness perceptions between different LTCs.

Due to the dearth of literature concerning illness perceptions between health conditions, the hypotheses for this pilot study are based upon the medical differences between the two conditions. Consequently, it was hypothesised that:

1. Parental illness perceptions concerning identity, control, and consequences will vary between T1D and JIA groups
2. Parental illness perceptions concerning cause and timeline will not vary between T1D and JIA groups



## **Method**

### **Ethical Approval**

This study received approval from the Health Research Authority (HRA; see Appendix H), the University of Bath Ethics Committee (see Appendix I), and University Hospitals Bristol NHS Foundation Trust.

### **Patient and Public Involvement**

Two parents whose children had LTCs were involved in the development of the study design through piloting and feedback.

### **Design**

The study used a between-groups comparison design. There were two groups:

1. Parents of CYP with a diagnosis of T1D
2. Parents of CYP with a diagnosis of JIA

### **Participants**

Participants were parents or guardians of CYP aged 11-18 with a diagnosis of T1D or JIA, being cared for by the paediatric diabetes or rheumatology teams at University Hospitals Bristol NHS Foundation Trust.

Potential participants were excluded if they were unable to provide consent to participate, or to read English fluently, due to resource limitations.

### **Materials**

Illness perceptions were measured using a version of the Brief Illness Perceptions Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006). The brief measure was used due to the limited time available for study participation. The BIPQ consists of items which map directly onto the illness perceptions outlined in the CSM, and three additional subscales (‘coherence’, measuring self-reported illness perceptions, and two subscales of emotional representations (‘illness concern’ and ‘emotional representation’) (Moss-Morris et al., 2002)). These subscales were included in the revised version of the illness perceptions questionnaire, but do not correspond directly to the five cognitive illness perceptions originally described in the CSM. As these perceptions are the focus of this study, the additional subscales included in the BIPQ were not analysed further. The

measure was adapted for use with parents by changing each item to refer to ‘their child’s’ illness. Additionally, two subscales (‘personal control’ and ‘consequences’) were expanded into two items per subscale, two regarding parental personal control and consequences, and two regarding personal control and consequences for their child. Adaptations were based on previous research into illness perceptions of caregivers (Richardson et al., 2015) and permissions granted (see Appendix J).

Anxiety and mood were assessed using the Generalised Anxiety Disorder 7 (GAD-7; (Spitzer, Kroenke, Williams, & Lowe, 2006) and the Patient Health Questionnaire-9 (PHQ-9; (Kroenke, Spitzer, & Williams, 2001). Both measures are validated and widely used clinically to assess anxiety and mood in adults.

## **Procedure**

All study materials were presented on via computer tablet using the online platform ‘Qualtrics’.

Potential participants were any eligible parents attending hospital appointments with their child. Prior to each clinic, the treating consultant and medical team were consulted to establish which parents would be suitable to approach as potential participants. Families were approached if, following clinical discussion, the medical team were satisfied participation was unlikely to be disruptive or distressing. The remaining eligible participants were approached in the waiting area and given study information by a researcher (a trainee clinical psychologist, clinical psychologist, or specialist nurse from their medical team). If parents indicated they would like to take part after receiving this information, informed consent for participation was taken and participants completed the questionnaires electronically before being debriefed.

## **Analysis**

Statistical analysis used SPSS v.24 for Windows. The planned ANCOVA (with mood, anxiety and time since diagnosis as covariates) was rejected as one covariate (mood) was not independent from the independent variable. Therefore, a one-way ANOVA was used. Bonferroni corrections were applied on the six subscales for which between-group differences were predicted, to protect against inflated type I errors, but not for comparisons where differences were not predicted. The cause subscale provided categorical data, so a Chi-squared test was used instead. Hierarchical multiple regressions were then conducted on subscales associated with the hypotheses. These regressions included mood, anxiety, and time since diagnosis as control variables and diagnosis as a predictor variable, to

establish whether diagnosis predicted significant amounts of variance in subscale scores after controlling for other variables.

A priori power calculations using G\*Power indicated a minimum sample size of 65 participants per group would be needed to achieve a power of 0.8,  $\alpha=0.05$  and an expected moderate effect size of 0.4.

## Results

### Sample Characteristics

In total, 43 parent/carers participated in the T1D group, and 37 in the JIA group. Participant characteristics are summarised in Table 1.

Participants did not significantly differ between groups in age ( $\chi^2(4)=2.129$ ,  $p=.712$ ), gender ( $\chi^2(1)=.347$ ,  $p=.556$ ), education ( $\chi^2(5)=4.476$ ,  $p=.483$ ), type of employment ( $\chi^2(3)=4.505$ ,  $p=.212$ ) or ethnicity ( $\chi^2(5)=4.052$ ,  $p=.542$ ). Their children did not significantly differ in age ( $t(66)=.695$ ,  $p=.490$ ), ethnicity ( $\chi^2(5)=4.052$ ,  $p=.542$ ), time since diagnosis (bootstrapped  $t(48.137)=.776$ ,  $p=.450$ ), and school attendance percentages (bootstrapped  $t(66)=.111$ ,  $p=.900$ ). However, the gender split between young people with T1D and JIA was significant ( $\chi^2(1)=4.017$ ,  $p=.045$ ), with a greater percentage of the JIA CYP sample being female. Such a difference has been documented in wider paediatric T1D and JIA populations (Kahn, 2013; Soltesz et al., 2007).

The parents of CYP with T1D had significantly higher total PHQ-9 scores than the JIA group ( $t(68.375)=2.083$ ,  $p=.041$ ). However, there was no significant difference between groups on total GAD scores ( $t(78)=1.056$ ,  $p=.294$ ).

Table 1.

*Participant and child characteristics presented for both T1D and JIA samples. Mean values are followed by standard deviations in parentheses.*

	<b>T1D</b>	<b>JIA</b>
<b>Participant Characteristics</b>		
Age	18-24 0%	18-24 2.7%
	25-34 9.5%,	25-34 13.5%
	35-44 38.1%	35-44 32.4%
	45-54 50%	45-54 45.9%
	55-64 2.4%	55-64 5.4%
Gender	Male 21.4%	Male 16.2%
	Female 78.6%	Female 83.8%
Education	Secondary school 21.4%	None 8.1%
	College 31.0%	Secondary school 18.9%
	University 28.6%	College 27.0%
	Professional/vocational 16.7%	University 21.6%
	Prefer not to say 2.4%	Professional/vocational 18.9%
		Prefer not to say 5.4%
Employment	Employed 66.7%	Employed 78.4%
	Self-employed 7.1%	Self-employed 10.8%
	Unemployed 9.5%	Unemployed 8.1%
	Other 16.7%	Other 2.7%
Ethnicity	White British 90.5%	White British 89.2%
	White Other 4.8%	White Other 5.4%
	Black Caribbean 2.4%	Indian 2.7%
	Mixed Other 2.4%	Pakistani 2.7%
<b>Child Characteristics</b>		
Age	13.97 (1.828)	13.69 (1.512)
Gender	Male 42.9%	Male 21.6%
	Female 57.1%	Female 78.4%
Ethnicity	White British 95.2%	White British 94.6%
	White Other 4.8%	Mixed Other 2.7%
		Pakistani 2.7%
Time since diagnosis (years)	4.94 (3.070)	5.78 (5.352)
School attendance (%)	87.56 (20.806)	87.09 (13.107)

### Between-Group Analyses

Between-group questionnaire scores are summarised in Table 2. The subscale data was screened for normality using histograms. In most cases the assumption of normality was violated, and this was not resolved by attempts to transform the data. Therefore, untransformed data was used and the one-way ANOVA p values were bootstrapped based on 1000 bootstrap samples. Homoscedasticity was assessed using Levene's test. Variances

were unequal for the timeline ( $F=76.330, p<.001$ ) and child personal control subscales ( $F=9.858, p=.002$ ), so equal variances were not assumed in these cases.

Table 2.

*Participant scores on measures, presented for both T1D and JIA samples. Mean values are followed by standard deviations in parentheses.*

	<b>T1D</b>	<b>JIA</b>
<b>BIPQ Subscales</b>		
Parent consequences	6.56 (2.193)	5.11 (2.193)
Child consequences	7.44 (2.314)	5.91 (2.548)
Timeline	9.85 (0.478)	7.63 (2.533)
Parent control	5.27 (2.225)	4.14 (2.603)
Child control	5.76 (1.685)	4.20 (2.795)
Treatment control	8.49 (1.938)	7.66 (2.141)
Identity	6.59 (2.439)	5.60 (2.488)
Illness concern	7.85 (2.209)	7.00 (2.473)
Coherence	8.44 (1.550)	7.74 (1.868)
Emotional representation	7.32 (2.360)	6.11 (2.643)
Cause	Frequencies of causes: Unknown 12 Genetic/hereditary 17 Health event 17 Life event/lifestyle 5	Frequencies of causes: Unknown 9 Genetic/hereditary 9 Health event 17 Life event/lifestyle 6
<b>Additional Measures</b>		
PHQ-9 (total score)	6.44 (6.185)	4.14 (3.529)
GAD-7 (total score)	4.93 (4.469)	3.86 (4.535)

**Hypothesis 1.** Bonferroni corrections for multiple comparisons indicate the acceptable alpha level was .008. Parents of CYP with T1D scored significantly higher on the child consequences subscale of the BIPQ than the JIA group ( $t(74)=2.733, p=.008$ ). Between-group differences were not found for the remaining subscales (parent consequences ( $t(74)=2.783, p=.009$ ), parent personal control ( $t(74)=2.033, p=.061$ ), child personal control ( $t(53.955)=2.878, p=.009$ ), treatment control ( $t(74)=1.775, p=.080$ , identity ( $t(74)=1.739, p=.086$ )).

**Hypothesis 2.** Parents of CYP with T1D scored significantly higher on the timeline subscale of the BIPQ compared to the JIA group ( $t(36.066)=5.120, p=.001$ ).

For the cause subscale, participants provided up to three possible causes for their child's health condition. Twenty percent of participants gave no answer on this subscale, so the analysis contains substantial amounts of missing data. Nevertheless, all causes

provided were categorised into one of four groups (cause unknown, genetic/inherited, caused by a specific health event (e.g. illness, vaccination, injury), or caused by lifestyle factors (e.g. life stressors, diet)). Category frequencies were tallied and are presented in Table 2. No significant between-group differences were found ( $\chi^2(3)=1.917, p=.603$ ).

### Hierarchical Multiple Regressions

As most of the data were not normally distributed, bootstrapped regressions were used. All regression models demonstrated acceptable independence of residuals (all Durbin-Watson test results were  $>1$  and  $<3$ ) and lack of multicollinearity (all VIF outcomes were  $<10$ ). For each regression model, results for Model 1 (control variables only: PHQ-9 total scores, GAD-7 total scores, and time since diagnosis) are reported, followed by Model 2 (control variables, plus diagnosis as a predictor variable). The significance of change statistics between the two models, with bootstrapped p values, are also reported.

**Parent Consequences.** Both models were significant (Model 1:  $R^2=.287, F(3, 75)=10.059, p<.001$ ; Model 2:  $R^2=.323, F(4,75)=8.825, p<.001$ ). Adding diagnosis to the first model did not account for a significant amount of variance ( $F(1,74)=3.940, p=.059$ ). This suggests between-group differences were not a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 3. The model suggests PHQ-9 total scores were the only significant predictor of parent consequences scores ( $t=2.636, p=.008$ ). Diagnosis ( $t=1.985, p=.059$ ), GAD-7 total scores ( $t=0.970, p=.335$ ) and time since diagnosis ( $t=1.867, p=.052$ ) were not significant predictors.

Table 3.

*Linear model of predictors of parent consequences subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	6.535 (4.512, 8.438)	.949		.001
Diagnosis	-.913 (-1.872, .010)	.476	-.196	.059
PHQ-9 (total score)	.162 (.034, .287)	.063	.361	.008
GAD-7 (total score)	.068 (-.062, .219)	.070	.130	.292

Time since diagnosis	-.101	.051	-.179	.052
	(-.190, -.015)			

**Child Consequences.** Both models were significant (Model 1:  $R^2=.253$ ,  $F(3, 75)=8.462$ ,  $p<.001$ ; Model 2:  $R^2=.291$ ,  $F(4,75)=7.576$ ,  $p<.001$ ). Adding diagnosis to the first model accounted for a significant amount of variance ( $F(1,74)=3.928$ ,  $p=.050$ ). This suggests between-group differences were a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 4. The model suggests diagnosis ( $t=1.982$ ,  $p=.050$ ), PHQ-9 total scores ( $t=2.869$ ,  $p=.008$ ), and time since diagnosis ( $t=2.550$ ,  $p=.042$ ) were all significant predictors of child consequences scores. GAD-7 total scores were not a significant predictor ( $t=2.550$ ,  $p=.042$ ).

Table 4.

*Linear model of predictors of child consequences subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	7.975 (5.984, 10.013)	.964		.001
Diagnosis	-.988 (-1.911, -.072)	.501	-.200	.050
PHQ-9 (total score)	.191 (.051, .325)	.067	.402	.008
GAD-7 (total score)	-.011 (-.167, .134)	.073	-.020	.871
Time since diagnosis	-.149 (-.298, -.012)	.071	-.250	.042

**Timeline.** Both models were significant (Model 1:  $R^2=.169$ ,  $F(3, 75)=5.079$ ,  $p=.003$ ; Model 2:  $R^2=.442$ ,  $F(4,75)=14.665$ ,  $p<.001$ ). Adding diagnosis to the first model accounted for a significant amount of variance ( $F(1,74)=36.262$ ,  $p=.001$ ). This suggests between-group differences were a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 5. The model suggests diagnosis ( $t=6.022$ ,  $p=.001$ ) and time since diagnosis ( $t=3.781$ ,  $p=.001$ ) were significant predictors of timeline scores. PHQ-9 total scores ( $t=0.846$ ,  $p=.374$ ) and GAD-7 total scores ( $t=0.429$ ,  $p=.760$ ) were not significant predictors.

Table 5.

*Linear model of predictors of timeline subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	10.870 (9.881, 11.941)	.519		.001
Diagnosis	-2.316 (-3.029, -1.646)	.393	-.539	.001
PHQ-9 (total score)	.043 (-.035, .151)	.049	.105	.374
GAD-7 (total score)	.025 (-.147, .169)	.080	.052	.760
Time since diagnosis	.171 (.056, .284)	.047	.329	.001

**Parent Control.** Model 1 was not significant, but Model 2 was significant (Model 1:  $R^2=.077$ ,  $F(3, 75)=2.099$ ,  $p=.107$ ; Model 2:  $R^2=.131$ ,  $F(4,75)=2.789$ ,  $p=.032$ ). Adding diagnosis to the first model accounted for a significant amount of variance ( $F=(1,74) 4.558, p=.042$ ). This suggests between-group differences were a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 6. The model suggests diagnosis ( $t=2.135$ ,  $p=.042$ ) and GAD-7 total scores ( $t=1.854$ ,  $p=.047$ ) were significant predictors of parent personal control scores. PHQ-9 total scores ( $t=1.690$ ,  $p=.091$ ) and time since diagnosis ( $t=1.796$ ,  $p=.064$ ) were not significant predictors.

Table 6.

*Linear model of predictors of parent personal control subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	7.041 (4.992, 9.191)	1.003		.001
Diagnosis	-1.153 (-2.223, -.109)	.572	-.539	.042
PHQ-9 (total score)	-.122 (-.260, .008)	.071	-.262	.091
GAD-7 (total score)	.152 (.015, .341)	.080	.282	.047



Time since diagnosis	-.114	.061	-.195	.064
	(-.218, -.006)			

**Child Control.** Both models were significant (Model 1:  $R^2=.084$ ,  $F(3, 75)=3.329$ ,  $p=.042$ ; Model 2:  $R^2=.219$ ,  $F(4,75)=6.320$ ,  $p=.000$ ). Adding diagnosis to the first model accounted for a significant amount of variance ( $F(1,74)=13.571$ ,  $p=.002$ ). This suggests between-group differences were a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 7. The model suggests diagnosis ( $t=3.684$ ,  $p=.002$ ), PHQ-9 scores ( $t=2.711$ ,  $p=.007$ ), and time since diagnosis ( $t=2.503$ ,  $p=.015$ ) were all significant predictors of child personal control scores. GAD-7 scores were not found to be a significant predictor ( $t=1.516$ ,  $p=.061$ ).

Table 7.

*Linear model of predictors of child personal control subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	9.098 (7.484, 10.638)	.808		.001
Diagnosis	-1.861 (-2.867, -.703)	.537	-.384	.002
PHQ-9 (total score)	-.182 (-.306, -.067)	.064	-.393	.007
GAD-7 (total score)	.116 (-.024, .261)	.066	.216	.061
Time since diagnosis	-.148 (-.265, -.035)	.059	-.254	.015

**Treatment Control.** Both models were not significant (Model 1:  $R^2=.019$ ,  $F(3, 75)=.492$ ,  $p=.689$ ; Model 2:  $R^2=.073$ ,  $F(4,75)=1.459$ ,  $p=.223$ ). Adding diagnosis to the first model accounted for a significant amount of variance ( $F(1,74)=4.295$ ,  $p=.044$ ). This suggests between-group differences were a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 8. The model suggests diagnosis ( $t=2.072$ ,  $p=.044$ ) was a significant predictor of treatment control scores. PHQ-9 scores ( $t=2.711$ ,  $p=.007$ ), GAD-7

scores ( $t=1.516, p=.061$ ) and time since diagnosis ( $t=2.503, p=.015$ ) were not found to be significant predictors.

Table 8.

*Linear model of predictors of treatment control subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	9.267 (7.877, 11.377)	.859		.001
Diagnosis	-1.012 (-2.018, -.102)	.481	-.384	.044
PHQ-9 (total score)	-.020 (-.152, .099)	.064	-.049	.758
GAD-7 (total score)	.051 (-.106, .202)	.079	.108	.474
Time since diagnosis	-.042 (-.173, .099)	.068	-.082	.552

**Identity.** Both models were significant (Model 1:  $R^2=.145, F(3, 75)=4.236, p=.008$ ; Model 2:  $R^2=.162, F(4,75)=3.566, p=.010$ ). Adding diagnosis to the first model did not account for a significant amount of variance ( $F(1,74)=1.477, p=.248$ ). This suggests between-group differences were not a significant predictor in the model when mood, anxiety and time since diagnosis were controlled for. The full model of predictor and control variables is in Table 9. The model suggests time since diagnosis is a significant predictor of identity scores ( $t=2.169, p=.020$ ). Diagnosis ( $t=1.215, p=.248$ ), PHQ-9 scores ( $t=1.560, p=.119$ ) and GAD-7 scores ( $t=.307, p=.815$ ) were not found to be significant predictors.

Table 9.

*Linear model of predictors of identity subscale scores, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors based on 1000 bootstrap samples.*

	<i>b</i>	<i>SE B</i>	$\beta$	<i>p</i>
(Constant)	7.126 (5.146, 9.159)	1.053		.001
Diagnosis	-.653 (-1.874, .533)	.561	-.133	.248
PHQ-9 (total score)	.112 (-.038, .279)	.074	.238	.119

GAD-7 (total score)	.025 (-.180, .188)	.103	.046	.815
Time since diagnosis	-.137 (-.242, -.024)	.058	-.231	.020

## Discussion

Overall, between-group analyses found an anticipated difference in illness perceptions in child consequences, with the JIA group predicting significantly less severe illness consequences than the T1D group. However, no further predicted between-group differences were found for the consequences, control, or identity dimensions. Unexpectedly, there was a difference in the timeline subscale, with the T1D group predicting significantly longer illness duration than the JIA group. However, as PHQ-9 scores were also significantly higher in the T1D group, it is difficult to draw conclusions based on between-group analyses which did not account for extraneous variables such as differences in parental depression scores. Therefore, analyses of which variables predicted subscale scores will also be discussed.

### Consequences

Differences between groups on consequences subscale scores were predicted but only found for the child consequences subscale in between-group analyses. However, analyses did find significant predictor variables for each consequences subscale.

**Parent Consequences.** The perceived severity of parental consequences was predicted by mood. If a parent reported lower mood, this predicted perceiving the consequences of the LTC for their life as more severe. This might be expected as mood can be related to negative cognitions (Beck, 1976), so parental mood predicting negative illness perceptions is understandable.

**Child Consequences.** Consequence perceptions for children were similarly predicted by mood, so parents with lower mood were more likely to perceive more severe consequences for their child.

Child consequences perceptions were also predicted by diagnosis. Parents of CYP with T1D were more likely to view the consequences for their child as more severe. This finding would be expected given only poorly managed T1D can be fatal and parental

illness perceptions can be more negative when the potential complications of a condition are objectively worse (Graziano et al., 2016).

Child consequences scores were also predicted by the duration of the LTC. If CYP had their condition for longer, their parent viewed the consequences for their child as less severe. This may be because families can adjust and achieve more realistic illness perceptions with more time. Alternatively, it is possible the severe consequences of a condition are less salient once families have had a condition for longer. Research suggests many parents of newly-diagnosed CYP with T1D and JIA experience high stress levels which then improve with time (Pelaiez-Ballestas et al., 2006; Whittemore, Jaser, Chao, Jang, & Grey, 2012). However, the adjustment process differs between families (Pelaiez-Ballestas et al., 2006), so further research is needed to capture the clinical implications of this finding.

## **Control**

Differences between the groups on control subscale scores were also predicted but not found in between-group analyses. However, analyses again found significant predictor variables for each control subscale.

**Treatment Control.** Neither regression model significantly predicted treatment control subscale scores. However, on examination of the individual variables, diagnosis significantly predicted treatment control variance. Parents of CYP with T1D perceived higher treatment control than the JIA group. This finding might be expected given the between-group differences in treatments; families must take a more active role in the treatment of T1D than for JIA. Control perceptions can vary in people receiving different treatments for chronic kidney disease with differing levels of treatment burden (Jansen et al., 2013), so further research is needed to explore which treatment factors influence control perceptions.

**Parent Control.** The control parents felt over their child's condition was similarly predicted by diagnosis; parents of CYP with T1D felt they had more control than the JIA group.

Parental control was also predicted by anxiety. If a parent was more anxious, they were more likely to perceive themselves as having greater control. Whilst this finding appears contrary to the general anxiety literature, which suggests an external locus of control is associated with higher levels of anxiety (Chorpita & Barlow, 1998), this literature may not capture the relationship between control and anxiety in T1D. Higher rates of parental T1D monitoring behaviours are associated with greater parental anxiety

(e.g. Monaghan, Hilliard, Cogen, & Streisand, 2009), which can disrupt familial effective T1D management. Clinically, this has implications for how illness control perceptions may require LTC specific intervention, as the relationship between control and anxiety may differ between LTCs.

**Child Control.** The amount of control parents felt their child had of their condition was also predicted by diagnosis; as might be expected, parents of CYP with T1D felt their child had more control than the JIA group.

Parental perceptions of CYP control were also predicted by mood. If a parent's mood was lower they were more likely to perceive their child as having less control. Research has suggested lower mood is associated with an external locus of control (Benassi, Sweeney, & Dufour, 1988), so parents with lower mood may attribute control of the condition to factors external to their child.

Child personal control was also predicted by duration of the LTC, with longer duration predictive of less control. This is an interesting finding, and it is unclear whether this interacts with views about remission. If a parent expects a condition to go into remission, they may view longer illness duration as indicative of poorer control, whereas if a parent does not perceive remission as a goal of treatment, longer illness duration may be associated with growing confidence in self-management. It would be interesting to explore whether these perceptions interact with the age of a child, as control perceptions may be influenced by younger children having less responsibility, or indeed teenagers engaging in fewer self-management behaviours (Hamilton & Daneman, 2002). Further research is needed to understand this finding.

## **Identity**

Differences between groups were predicted for identity subscale scores but not found in the between-group analyses. However, analysis of predictor variables showed time since diagnosis significantly predicted identity subscale scores. Parents of CYP diagnosed for longer reported their child experienced fewer symptoms. This finding may suggest a trend for LTCs to be better managed with more experience, and for this experience to feed-back and update illness perceptions as predicted by the CSM. However, further research would be needed to confirm this interpretation.

## **Timeline**

Parents of CYP with T1D felt the condition would last significantly longer than parents of CYP with JIA. This finding was not predicted. However, this outcome could be

understood by considering the distinction between cure and remission. LTCs cannot be cured and can have a long duration, and so no between-group difference was hypothesised based on this rationale. However, symptom remission can be achieved in JIA but not T1D. This finding may suggest illness perceptions are more affected by the lived experience of symptoms than the medical distinction between curability and remission. There can be substantial variation in symptom remission between different incurable LTCs, and these differences in potential remission could affect illness perceptions related to expected duration. However, the direction of causality between illness perceptions and remission needs to be considered carefully, as the CSM would propose illness perceptions to be predictive of positive health behaviours which would increase the likelihood of remission. Moreover, illness perceptions can be negative even when conditions are in remission (Tiemensma et al., 2011), so further research is needed to understand the relationship between predicted timelines, health outcomes, and the relationship between curability and remission in LTCs.

Finally, the expected timeline of the LTC was predicted by time since diagnosis. As might be expected, if a child had already had their LTC for a longer time, their parent was more likely to predict it would last longer overall.

## **Cause**

As predicted, there were no significant differences between the two conditions on the cause subscale. Most parents in both conditions viewed the cause to be unknown, which reflects current medical understanding. However, some parents endorsed genetic or environmental factors, both of which are implicated as possible causes in the literature. Despite minimal knowledge of the causes of either condition, healthcare professionals should nevertheless explore cause beliefs, as inaccuracies may have unhelpful implications for effective health management behaviours.

## **Limitations**

There are several limitations with this study. Firstly, the study was underpowered, so non-significant findings may be subject to type II errors and therefore cannot be interpreted. It is feasible there are additional variables that could predict illness perceptions which were not controlled for in this study. In addition, the use of the Brief Illness Perceptions Questionnaire may mean parental illness perceptions were not explored in sufficient depth, particularly when there is minimal existing literature on the topic. Whilst the BIPQ is a validated measure and was chosen for its brevity, the full version of the

measure (IPQ-R, Moss-Morris et al., 2002) consists of multiple items for each perception category, and so may have offered richer information.

The recruitment strategy has implications for the external validity of the results. The study materials were only available in English, which limited the accessibility of the study. Recruitment only captured parents who attended healthcare clinics, and this likely biased the sample to parents proactively involved in their child's healthcare. Finally, all participants originated from one NHS trust, which has implications for the generalisability of the results.

The study only considered cognitive illness perceptions, which is a single component of the full CSM. Based on this pilot study alone, it is therefore not possible to fully understand how the CSM applies for parents, and further work is needed to explore systemic components of the entire model, which could include both parental and child coping, appraisals, and health outcomes. In addition, this study only considered parental illness perceptions, which are one small component of systemic understanding. Wider systemic factors were insufficiently varied in this study, as the sample used was predominantly white British and female, and future work would need to incorporate participants with diverse social and positions in society (social GRACES, Burnham 1992, 1993; Roper-Hall, 1998).

Finally, it is difficult to interpret the analyses of between-group differences when the T1D group scored significantly higher on the PHQ-9 than the JIA group, as any differences may be a result of mood rather than the condition. It is also difficult to know whether it is a trend for T1D parents to be more depressed or not, and further work would be needed to understand this finding and the potential clinical implications of this.

## **Conclusions**

The findings of this pilot study are interesting, despite the study having a small scope and methodological limitations. The results suggest parental illness perceptions are complex, and different perception domains can be predicted by a variety of factors. The findings add to the existing literature which suggests illness perceptions can be predicted by the condition itself (e.g. Graziano et al., 2016), mood and anxiety (Arat et al., 2018), and duration of the condition (Fischer et al., 2010).

The findings, as a result of a pilot study, require extensive further research to fully understand their implications. Further to suggestions already discussed, future studies could examine parental illness perceptions of CYP with a range of LTCs to better understand variation between conditions. Additionally, exploring how parental illness

perceptions relate to CYP illness perceptions, parental and familial coping and child health outcomes would be important to build a systemic understanding of illness perceptions.

As well as indicating future research directions, the findings also offer some tentative clinical implications. The differences between LTCs in timeline and control domains suggest interventions targeted at these perceptions may need to be condition specific.. These could include education and support for families related to the expected duration of the condition and feasible expectations for personal and treatment control. These findings may also implicate the need for specific anxiety management interventions for parents with T1D in relation to parental control and associated anxiety and health behaviours. However, some of the findings suggest that condition-specific interventions may not always be necessary. Research suggests the illness perceptions of parents tend to be more negative in comparison to those of their children with the condition (Gaston et al., 2012; Law, 2002), so there may be aspects of being a parent of an ill child which affect illness perceptions independent of condition-specific factors. This may mean clinical interventions for these perceptions do not have to be specific to the LTC in question. For example, the finding that perceptions of consequences and child control are predicted by parental mood could suggest evidence-based interventions for mood should be available for parents of CYP with LTCs. These interventions would not necessarily need to be tailored to the specific LTC and could positively affect illness perceptions, which the CSM would predict could lead to more helpful coping strategies and improved health outcomes. Finally, despite the small scope of the study, the overall picture so far suggests that parental illness perceptions are not as ‘common sense’ as might be expected. Whilst further work is clearly needed to explore the model fully with parents and families, the complex picture emerging from the findings highlights the importance of parental illness perceptions to healthcare professionals. This increase in awareness of parental illness perceptions may support professionals to incorporate a systemic perspective when formulating and intervening with unhelpful health behaviours.

In summary, this pilot study explored differences in parental illness perceptions between two LTCs. The findings suggest some perceptions are affected by LTC-specific factors, whilst others are more affected by mood or general illness factors such as time since diagnosis. Further research is now needed to explore how these findings relate to the rest of the CSM and to further inform the tentative clinical implications of the findings so far. Nevertheless, the findings contribute to a growing evidence-base underpinning systemic application of the CSM, which is crucial to effectively support families to adapt to and manage LTCs.



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# Executive Summary

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Madeline Harris

M.G.Harris@bath.ac.uk

Department of Clinical Psychology

University of Bath

May 2018

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## Background

The 'Common Sense Model' (CSM; Leventhal, Meyer, & Nerenz, 1980) aims to explain how psychological factors influence long-term health condition (LTC) management. The model proposes a number of illness perceptions which are thought to inform a person's coping strategies and their appraisals regarding the success of these strategies. The CSM proposes that both cognitive and emotional components of illness perceptions can affect how people react to LTCs. There are five dimensions to the cognitive component of illness perceptions:

1. Identity: the perceived symptoms
2. Cause: attributions regarding illness cause
3. Consequences: perceptions of the wider effects
4. Timeline: beliefs concerning condition duration
5. Cure/Control: perceptions of curability or controllability via treatments and self-management

Research has shown the CSM applies to children and young people (CYP) as well as adults. However, the model does not incorporate systemic factors, which are especially relevant for CYP, for whom families hold more illness management responsibilities. Caregiver perceptions of an illness have been linked with outcomes for the person with the health condition, including their self-care, their own illness perceptions, quality of life outcomes, and familial management of the health condition. Additional factors which may explain variation between illness perceptions is the LTC itself, as some illnesses are likely to be perceived more negatively than others. In addition, variables such as mood, anxiety and time since diagnosis have also been shown to influence illness perceptions.

There is a dearth of research exploring illness perceptions of parents and wider systems between different LTCs. Whether parental illness perceptions vary between health conditions is unknown, and this has important clinical implications regarding ongoing support for families. This study is a pilot study which explores the cognitive component of parental illness perceptions.

This study examined the illness perceptions of parents whose children have either type 1 diabetes (T1D) or juvenile idiopathic arthritis (JIA). These are both autoimmune conditions of unknown cause, have no known cure, and require CYP and families to have ongoing involvement in managing the condition. However, there are differences between the conditions which were likely to affect illness perceptions, such as different symptoms, treatments and consequences of poor management. It was therefore hypothesised that

parental illness perceptions concerning identity, control, and consequences will vary between T1D and JIA groups, but would not on the cause and timeline dimensions.

## **Method**

The study used a between-groups comparison design. There were two groups:

3. Parents of CYP with a diagnosis of T1D
4. Parents of CYP with a diagnosis of JIA

Participants provided demographic information and completed measures of illness perceptions (adapted version of the Brief Illness Perceptions Questionnaire for parents), mood (PHQ-9) and anxiety (GAD-7).

## **Findings & Implications**

Differences were found between LTCs in the timeline and control domains. Having a child with T1D was predictive of anticipating a longer illness duration and perceiving greater personal, child and treatment control over the condition. In addition, having greater levels of anxiety was predictive of more perceived control, which may be associated with condition monitoring behaviours in T1D. These differences suggest some illness perceptions may require LTC-specific intervention when changing unhelpful illness perceptions. These could include education and support for families with regards to projected condition duration and feasible expectations for personal and treatment illness control. In T1D, these findings may also implicate the need for anxiety management interventions in relation to parental control.

Perceptions of parental and child consequences and child control were predicted by parental mood. Scores indicating lower mood predicted perceiving the consequences of the condition as more severe and lower levels of perceived control over the condition. These findings suggest evidence-based interventions for mood may be helpful for parents of CYP with LTCs. These interventions could positively affect illness perceptions, which the CSM would then predict could lead to more helpful coping strategies and an improvement in health outcomes.

Further research is now needed on the basis of this initial pilot study to explore the full CSM in parents and families.

# Connecting Narrative

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Madeline Harris  
M.G.Harris@bath.ac.uk

Department of Clinical Psychology  
University of Bath  
May 2018

**Word Count:** 2507



This connecting narrative is designed to provide a reflective account of my experience of the research process during training. I will discuss the four research components of the course in turn (critical review of the literature, service improvement project, main research project, and case studies) and then finish with my future research aspirations.

## **Critical Review of the Literature**

The process of coming up with an initial idea for a literature review was difficult for me. I hoped to do my review in the field of childhood trauma, and wanted to conceptualise a question which had a lot of direct clinical application. However, I was finding it challenging to bring these hopes together with a very rigorous and academic form of research. Trauma has attracted lots of research interest from a breadth of different psychological, medical and sociological perspectives, and there are a vast number of terms used to refer to these experiences in the literature. Trying to review this topic as a trainee was therefore impossible without narrowing down this broad topic in some way. By far the most difficult part of the entire review process for me was trying to come up with a review question which was unique, timely, and feasible to carry out. This process is difficult enough for seasoned researchers, but as there were no fields of which I had a good understanding of the existing literature at the time, many hours were spent trying to understand different fields of work to only find the review opportunities were limited. This was, at times, a frustrating and sometimes demoralising process.

The topic of childhood maltreatment and eating disorders was eventually chosen as it linked with one supervisor's clinical area of expertise. Eating disorders was also an area of interest of mine following my inpatient CAMHS placement in which many young people had experienced childhood maltreatment and had gone on to develop a serious and life-threatening eating disorder. Whilst the link between childhood maltreatment and eating disorders appeared evident in the literature, there did not appear to be a review of what other variables may mediate this relationship.

Once I had settled on a feasible research question, the review itself was relatively straightforward. We approached Glenn Waller for some guidance around whether the review would be a unique and valuable contribution to the literature, and he felt it was an area worth exploring further. I sought advice from the university library around an appropriate review strategy and from there, the review went fairly smoothly.

I was pleased when, at the end of the review process, the findings appeared to have the potential to make a meaningful contribution to the field. I have seen first hand how

interventions for eating disorders with people who have a history of maltreatment are often not as successful as one might hope. My review can contribute to the existing literature by suggesting that certain psychological variables might mediate the relationship between a history of maltreatment and eating disorders, and these variables may require consideration and intervention when working clinically with this population.

### **Service Improvement Project**

I completed my service improvement project with the service I joined on my very first placement. From early in the placement, I had talked with my supervisor about her role within the team to support team formulation and reflective practise. We identified that a SIP could be a useful way of working out how the psychologists could best to support the team with this. We decided to use focus groups to ask staff about their experiences of team formulation, what helped them to formulate and what made the process more difficult. We felt it was important staff could be honest and give anonymous feedback, and so I ran the focus groups without any involvement from the other team psychologists. The rationale for this was that staff might be reluctant to share constructive criticism in a focus group facilitated by the same person who provided their formulation training or led their reflective practise sessions. By the time I ran the focus groups, I was no longer in the team and it was felt I was suitably removed from the other psychologists to be able to facilitate these groups.

I was aware how difficult it can be to try and engage very busy clinicians with research. I was therefore pleased and quite touched by how the teams had taken the time to prioritise my research and attend the focus groups – if anything, I had too many people attend rather than too few! I think this is testament to how important it is to know the team beforehand when conducting research, as I doubt a team who did not know me would have afforded me the same opportunity. I also think this reflects how the team valued psychological support and input, and the conversations which emerged from the focus groups were full of rich themes and ideas which had not occurred to me or my supervisor during our own reflections.

I appreciated how the project aims were best addressed by a qualitative methodology. I did not have experience of qualitative methods prior to the course, and so I am pleased I had the opportunity to gain experience of these methods during training. I am very grateful to my supervisors for supporting me through this process, and I found it fascinating to draw such a rich amount of data from the focus group conversations. As a

result of this project, I feel a lot more confident to use qualitative research methods again in the future.

Feeding back the results to a steering group of psychologists in the trust was interesting, as many of the psychologists were at the point of establishing team formulation and reflective practise in their own teams and so could make good use of the recommendations themselves. The entire process has therefore highlighted the value of service level projects, as the findings be incredibly useful for the team in question but can nevertheless have applications for other teams too.

## **Main Research Project**

I wanted to do my main research project in the field of paediatric health, as this was an area I had worked in prior to training. In particular, my experience had shown how crucial the wider families and systems are when providing psychological support in healthcare, and I was keen to further explore systemic factors in this area. In conversations with regional supervisors, the importance of parental perspectives and how these are sometimes overlooked in paediatric health research was explored and became a focus of my research.

I found the proposal review process to be quite challenging. Substantial changes to my project were recommended, and these changes were a very good idea as my project was far too ambitious. However, there were a number of last-minute changes to the deadlines for my proposal resubmission. This was one of the most difficult periods of training for me, as I felt unsupported and under unnecessary pressure to meet arbitrary course deadlines. I met the deadlines as best I could, and was able to talk about the strain this had put on me with my supervisors, but I think the entire process hindered me from thinking freely about this project for months. After this period of intense stress, I felt I needed a break from the project, but I had been advised to start the ethical approval process as quickly as possible and so I did this without revisiting the project first. Looking back, I wonder if I could have made some additional adjustments to the project, for example incorporating measures which tapped into other components of the common sense model (e.g. coping) in order to more fully explore more components of the CSM in parents.

The ethical approval process, whilst not academically demanding, was nevertheless tricky and I remain grateful to my cohort for the support we offered each other with this. I did not need to attend a REC panel in person, as my study was eligible for proportionate review. It was interesting that the study achieved all the ethical approvals from the HRC, only to then still require substantial review at trust level prior to recruitment being allowed

to start. It was my understanding the lengthy REC and HRC approvals processes were in place to minimise the amount of bureaucracy at trust level, but in my experience this was not the case.

After many months spent gaining ethical approval, I was able to begin recruitment in June 2017. The original agreement was that my regional supervisors would recruit participants whilst they were waiting for outpatient clinic appointments. I attended a number of outpatient clinics to support recruitment over the summer during study days, which helped the recruitment rates for both groups. Recruitment for my diabetes group was complete by the end of the summer, but it became apparent that there were higher volumes of people available in the diabetes group than the JIA group. Coupled with no record of which patients had a diagnosis of JIA under the rheumatology team (aside from accessing each patient's notes individually), this meant identifying eligible participants was difficult. I was lucky to be on placement at Bristol Children's Hospital from October 2017-March 2018, and so was on site to be able to support recruitment. It became apparent that the recruitment process we had originally planned was not sustainable, and it is very fortunate I was available to recruit too. If I had not been able to recruit during my placement, I am doubtful I would have achieved adequate numbers in this group to be able to run parametric statistical analyses. The process highlighted the difficulties of doing research in the NHS – even large teaching hospitals sometimes lack basic processes (e.g. a database of each patient and their diagnosis) which would make research a lot easier. Clinical staff are under such incredible demands in a political context which means the NHS is inadequately resourced already, and so the capacity for services to participate in research with no funding is limited. Without the goodwill of the paediatric diabetes and rheumatology teams, I am not convinced I would have been able to recruit the numbers of participants that I did. I remain very grateful to these teams for all their support.

The analysis stage of the project was a steep learning curve for me. I had researched the statistical analyses I hoped to use but found my data did not meet the necessary assumptions and I could not use my planned analysis methods. Through the process of devising an alternative plan which aimed to answer my research questions without misusing statistical methods, I became increasingly aware of how there are very few straightforward answers in statistical analysis in psychology at doctoral level. I found the lack of statistical support available within the course team surprising, as the course requires trainee main research projects to use quantitative methods and yet appeared unable to readily supervise the analysis of these designs. However, I am pleased to have gained

such in-depth statistical knowledge and experience of managing my own analysis process, and I hope to take this experience forward in any future research projects.

Looking back over the whole project, I am pleased the results could have important clinical applications despite the difficulties along the way. I learned a lot about conducting research in the NHS as a result of this project, and I will be able to take forward these lessons into my future career. Both the Paediatric Diabetes and Rheumatology teams at Bristol Royal Hospital for Children have requested I present the findings at their team meetings, and I am looking forward to discussing the results and hearing their views on the implications these findings could have for their clinical practise.

## **Case Studies**

I found the opportunity to write a case study on each placement very appealing, as it was incredibly interesting to reflect more deeply on my clinical work. I think the process was crucial in truly enabling me to develop theory-practise links, which I was then able to use in my future clinical work.

However, there were certain elements of the case studies which proved trickier for me. In particular, I found it challenging to produce two case studies which used a single case experimental design. I think the design lends itself to certain types of intervention (behavioural ones spring to mind!), and when the work is a bit more difficult to measure or quantify it can be a little more difficult to meaningfully use this design. However, I think the design is very valuable for capturing practise based research and disseminating it to inform the evidence base, and I am grateful to have been challenged to try and use it in my clinical practise.

Due to the BABCP requirements, it was mandatory that 4 of the 5 case studies were CBT based. Whilst this was an excellent learning opportunity and I am very grateful the course has worked so hard to incorporate the accreditation requirements into our course, there were a number of occasions when I felt this limited the cases I could write up. At times, I would have preferred to write a case study that was about a more complex case which did not necessarily fit into a CBT framework. Reflecting on complex cases which did not lend themselves as easily to routine outcome measures or established cognitive-behavioural models would have been an interesting learning and development opportunity. Some of the more complex pieces of work would routinely take up a lot of supervision and thinking on placement, and I would have welcomed the additional space to delve deeper into the theory-practice links in cases such as these. Having the opportunity to do this more often would have helped me reflect and learn from the more challenging placement

experiences, and I wonder if they would have had heuristic value of their own by virtue of the complexity of the case and how they related to existing models.

### **Future Research Aspirations**

My research experiences during training have taught me a lot about the practicalities of conducting clinical research. In particular, the ever-increasing demands on services seem to mean working clinically and being involved in research can be challenging despite the best of intentions. However, well conducted and clinically applicable research is crucial for generating an evidence-base which can support our clinical work, and contributing to this is an integral part of being a clinical psychologist. I truly appreciate how the course has exposed me to the different levels of research which can be done by clinical psychologists, from individual case studies, service level work, and academic reviews. Through these experiences, I have learned how different kinds of research have value, and can reflect on the multitude of ways I could contribute to the evidence base in the future. I am very grateful for the breadth of research skills I have gained during training, and hope to apply these throughout my career to continue to balance the clinical and research elements inherent to the role of a clinical psychologist.

# Acknowledgements

---

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Finally, to my all my wonderful friends and family. Thank you for your patience and for giving me a life outside of this process. I love you all so much, and I could not have done this without you.

# Appendix A: Critical Review of the Literature - European Eating Disorders Review Author Guidelines

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## 1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

**Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <http://mc.manuscriptcentral.com/erv>**

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## 2. AIMS AND SCOPE

*European Eating Disorders Review* provides an international forum for disseminating cutting-edge theoretical and empirical research that significantly advances understanding of the relationship between Eating Disorders and Abnormal Eating/Weight conditions and well-being in humans.

*European Eating Disorders Review* publishes authoritative and accessible articles, from all over the world, which review or report original research that has implications for the treatment and care of people with eating disorders and obesity, and articles which report innovations and experience in the clinical management of eating disorders. The journal focuses on implications for best practice in diagnosis and treatment. The journal also provides a forum for discussion of the causes and prevention of eating disorders, and related health policy.

Authors may submit original theoretical systematic reviews, methodological, or empirical research articles (7000 words or less) or short communications (3000 words or less). The journal also publishes invited conceptual reviews from leading worldwide researchers in the field of Eating Disorders and/or Obesity. The aims of the journal are to offer a channel of communication between researchers, practitioners, administrators and policymakers who need to report and understand developments in the field of eating disorders.

The journal

- Reports on useful research and experience related to the treatment and prevention of eating disorders in primary care and hospital settings, with special attention to therapy oriented translational research, high quality reviews, clinical trials and pilot innovative therapy approaches.
- Provides information about 'good practice' and systematic reviews.
- Offers a forum for new thinking about the nature, incidence, diagnosis and clinical management of eating disorders (namely anorexia nervosa, bulimia nervosa, binge eating disorders, OSFED and other abnormal eating or feeding behaviors associated with childhood and obesity).

## 3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

**Research articles** reporting new research of relevance as set out in the aims and scope should not normally exceed 6000 words (excluding abstract, references, tables or figures), with no more than five tables or illustrations. They should conform to the conventional layout: title page, Abstract, Introduction and Aims, Method, Results, Discussion, Acknowledgements and References. Each of these elements should start on a new page.

Word Limit: 6,000 (excluding abstract, references, tables or figures).

Abstract: 200 words.

References: up to 60.

**Review articles:** Systematic and meta-analytic review papers are welcomed if they critically review the available literature in a topic that will enhance clinical practice. Articles should have clear focus and enough number of studies should be available for a substantive review paper. Studies that only describe or list previous studies without a critical overview of the literature will not be considered.

Word Limit: 5,000 (excluding abstract, references, tables or figures).

Abstract: 200 words.

References: up to 100.

Figures/Tables: 5 maximum, but should be appropriate to the material covered. Additional tables



might be included as supplementary information, if needed. Review articles must follow the [PRISMA](#) Guidelines. Authors may want to have a look at the review check lists that reviewers when assessing review articles.

**Brief reports** should concisely present the essential findings of the author's work and be comprised of the following sections: Abstract, Introduction and Aims, Method, Results, Discussion, and References. Tables and/or figures should be kept to a minimum, in number and size, and only deal with key findings. In some cases authors may be asked to prepare a version of the manuscript with extra material to be included in the online version of the review (as supplementary files). Submissions in this category should not normally exceed 2500 words in length.

Brief reports bring with them a whole host of benefits including: quick and easy submission, administration centralised and reduced and significant decrease in peer review times, first publication priority (this type of manuscript will be published in the next available issue of the journal).

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- ii. A short running title of less than 40 characters;
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- iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- v. The corresponding author's contact email address and telephone number;
- vi. Acknowledgments;
- vii. Conflict of Interest statement (for all authors)
- viii. Names and grant numbers of any sources of funding or support in the form of grants, equipment, drugs etc.

##### **Authorship**

Please refer to the journal's authorship policy the [Editorial Policies and Ethical Considerations](#) section for details on eligibility for author listing eligibility.

##### **Acknowledgments**

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

##### **Conflict of Interest Statement**

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the [Editorial Policies and Ethical Considerations](#) section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

##### **Main Text File**

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

- i. Title, abstract, highlights and key words;
- ii. Main text;
- iii. References;
- iv. Tables (each table complete with title and footnotes);
- v. Figure legends;
- vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

##### **Abstract**

All manuscripts should contain an abstract of up to 200 words. An **abstract** is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work. It must be structured, under the sub-headings: Objective; Method; Results; Conclusions.

### **Highlights**

Highlights are mandatory for European Eating Disorders Review. These should appear as three bullet points that convey the core findings of the article.

### **Keywords**

Include up to five **keywords** that describe your paper for indexing purposes.

### **References**

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the [APA FAQ](#). Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

#### *Journal article*

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486. [doi:10.1176/appi.ajp.159.3.483](https://doi.org/10.1176/appi.ajp.159.3.483)

#### *Book*

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

#### *Internet Document*

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from <http://www.youtube.com/watch?v=Vja83KLQXZs>

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Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. [Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

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- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

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Authors; Year; Dataset title; Data repository or archive; Version (if any); Persistent identifier (e.g. DOI)

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Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.

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Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are expected to adhere to the following research reporting standards.

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- [COREQ](#) checklist for qualitative studies
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The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript.

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# Appendix B: Critical Review of the Literature - Search Strategy

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## Basic Search Terms

### *Child Maltreatment*

1. Child OR Childhood Abuse/Maltreatment/Harm/"Abused Child"
2. Child OR Childhood Neglect/Negligence/"Neglected Child"
3. Emotional Abuse/Emotional Maltreatment/Psychological Abuse/Psychological Maltreatment/Verbal Abuse
4. Physical Abuse/Maltreatment/Violence
5. Sex OR Sexual Abuse/Exploitation/Rape
6. Bullying/Cyberbullying /Peer Abuse
7. Domestic Violence/Domestic Abuse

### *Eating Disorders*

8. Eating Disorder/Disordered Eating
9. Anorexia/+ Nervosa/Anorexic
10. Bulimia/+ Nervosa/Bulimic
11. Binge Eating Disorder (BED)
12. Bingeing/Binging
13. Purging/Purgeing
14. Avoidant restrictive food intake disorder (ARFID)
15. Eating Disorder Not Otherwise Specified (EDNOS)
16. Other Specified Feeding or Eating Disorder (OSFED)

## Pubmed

1. "Domestic Violence"[MeSH Terms] OR "Adult Survivors of Child Adverse Events"[MeSH Terms] OR "Child Abuse"[All Fields] OR "Childhood Abuse"[All Fields] OR "Child Maltreatment"[All Fields] OR "Child Harm"[All Fields] OR "Abused Child"[All Fields] OR "Maltreated Child"[All Fields] OR "Maltreated Children"[All Fields]
2. "Child Neglect"[All Fields] OR "Childhood Neglect"[All Fields] OR "Neglected Child"[All Fields]
3. "Emotional Abuse"[All Fields] OR "Emotional Maltreatment"[All Fields] OR "Psychological Abuse"[All Fields] OR "Psychological Maltreatment"[All Fields] OR "Verbal Abuse"[All Fields]
4. "Physical Abuse"[MeSH Terms] OR "Physical Abuse"[All Fields] OR "Physical Maltreatment"[All Fields] OR "Physical Violence"[All Fields]
5. "Sex Offenses"[MeSH Terms] OR "Sex Abuse"[All Fields] OR "Sexual Abuse"[All Fields] OR "Sexual Exploitation"[All Fields] OR "Rape"[All Fields] OR "Sex Assault"[All Fields] OR "Sexual Assault"[All Fields]
6. "Bullying"[MeSH Terms] OR "Bully"[All Fields] OR "Bullying"[All Fields] OR "Cyberbullying"[All Fields] OR "Cyber Bullying"[All Fields] OR "Peer Abuse"[All Fields]
7. "Domestic Violence"[All Fields] OR "Domestic Abuse"[All Fields] OR "Family Violence"[All Fields] OR "Family Abuse"[All Fields]

8. "Feeding and Eating Disorders"[MeSH Terms] OR "Eating Disorder"[All Fields] OR "Eating Disorders"[All Fields] OR "Disordered Eating"[All Fields]
9. "Anorexia"[All Fields] OR "Anorexic"[All Fields]
10. "Bulimia"[All Fields] OR "Bulimic"[All Fields]
11. "Binge Eating Disorder"[All Fields]
12. "Binge"[All Fields] OR "Binging"[All Fields] OR "Bingeing"[All Fields]
13. "Purge"[All Fields] OR "Purging"[All Fields]
14. "Avoidant restrictive food intake disorder"[All Fields] OR "Avoidant/restrictive food intake disorder"[All Fields]
15. "Eating Disorder Not Otherwise Specified"[All Fields]
16. "Other Specified Feeding or Eating Disorder"[All Fields]

### **Actual Search:**

("Domestic Violence"[MeSH Terms] OR "Adult Survivors of Child Adverse Events"[MeSH Terms] OR "Child Abuse"[All Fields] OR "Childhood Abuse"[All Fields] OR "Child Maltreatment"[All Fields] OR "Child Harm"[All Fields] OR "Abused Child"[All Fields] OR "Maltreated Child"[All Fields] OR "Maltreated Children"[All Fields] OR "Child Neglect"[All Fields] OR "Childhood Neglect"[All Fields] OR "Neglected Child"[All Fields] OR "Emotional Abuse"[All Fields] OR "Emotional Maltreatment"[All Fields] OR "Psychological Abuse"[All Fields] OR "Psychological Maltreatment"[All Fields] OR "Verbal Abuse"[All Fields] OR "Physical Abuse"[MeSH Terms] OR "Physical Abuse"[All Fields] OR "Physical Maltreatment"[All Fields] OR "Physical Violence"[All Fields] OR "Rape"[MeSH Terms] OR "Sex Abuse"[All Fields] OR "Sexual Abuse"[All Fields] OR "Sexual Exploitation"[All Fields] OR "Rape"[All Fields] OR "Bullying"[MeSH Terms] OR "Bully"[All Fields] OR "Bullying"[All Fields] OR "Cyberbullying"[All Fields] OR "Cyber Bullying"[All Fields] OR "Peer Abuse"[All Fields] OR "Domestic Violence"[All Fields] OR "Domestic Abuse"[All Fields] OR "Family Violence"[All Fields] OR "Family Abuse"[All Fields]) AND ("Feeding and Eating Disorders"[MeSH Terms] OR "Eating Disorder"[All Fields] OR "Eating Disorders"[All Fields] OR "Disordered Eating"[All Fields] OR "Anorexia"[All Fields] OR "Anorexic"[All Fields] OR "Bulimia"[All Fields] OR "Bulimic"[All Fields] OR "Binge Eating Disorder"[All Fields] OR "Binge"[All Fields] OR "Binging"[All Fields] OR "Bingeing"[All Fields] OR "Purge"[All Fields] OR "Purging"[All Fields] OR "Avoidant restrictive food intake disorder"[All Fields] OR "Avoidant/restrictive food intake disorder"[All Fields] OR "Eating Disorder Not Otherwise Specified"[All Fields] OR "Other Specified Feeding or Eating Disorder"[All Fields])

### **PsycNet**

1. Index Term: Child Abuse  
All Fields: "Child Abuse" OR "Childhood Abuse" OR "Child Maltreatment" OR "Childhood Maltreatment" OR "Child Harm" OR "Abused Child" OR "Maltreated Child" OR "Maltreated Children"
2. Index Term: Child Neglect  
All Fields: "Child Neglect" OR "Childhood Neglect" OR "Child Negligence" OR "Childhood Negligence" OR "Neglected Child"
3. Index Term: Emotional Abuse; Verbal Abuse  
All Fields: "Emotional Abuse" OR "Verbal Abuse" OR "Psychological Abuse" OR "Emotional Maltreatment" OR "Psychological Maltreatment"
4. Index Term: Physical Abuse  
All Fields: "Physical Abuse" OR "Physical Maltreatment" OR "Physical Violence"
5. Index Term: Sex Offenses; Rape

- All Fields: "Sex Abuse" OR "Sexual Abuse" OR "Sex Exploitation" OR "Sexual Exploitation" OR "Rape" OR "Sex Assault" OR "Sexual Assault"
6. Index Term: Bullying; Cyberbullying  
All Fields: "Bully" OR "Bullying" OR "Cyber Bullying" OR "Cyberbullying" OR "Peer Abuse"
  7. Index Term: Domestic Violence  
All Fields: "Domestic Violence" OR "Domestic Abuse" OR "Family Violence" OR "Family Abuse"
  8. Index Term: Eating Disorders  
All Fields: "Eating Disorder" OR "Eating Disorders" OR "Disordered Eating"
  9. Index Term: Anorexia Nervosa  
All Fields: "Anorexia" OR "Anorexic"
  10. Index Term: Bulimia  
All Fields: "Bulimia" OR "Bulimic"
  11. Index Term: Binge Eating Disorder  
All Fields: "Binge Eating Disorder"
  12. Index Term: Binge Eating  
All Fields: "Binge" OR "Binging" OR "Bingeing"
  13. Index Term: Purging (Eating Disorders)  
All Fields: "Purge" OR "Purging" OR "Purgeing"
  14. All Fields: "Avoidant restrictive food intake disorder" OR "Avoidant/restrictive food intake disorder"
  15. All Fields: "Eating Disorder Not Otherwise Specified"
  16. All Fields: "Other Specified Feeding or Eating Disorder"

### **Actual Search:**

((Index Terms: ("Eating Disorders") OR Index Terms: ("Anorexia Nervosa") OR Index Terms: ("Bulimia") OR Index Terms: ("Binge Eating Disorder") OR Index Terms: ("Binge Eating") OR Index Terms: ("Purging (Eating Disorders)")) OR (Any Field: ("Eating Disorder") OR Any Field: ("Eating Disorders") OR Any Field: ("Disordered Eating") OR Any Field: ("Anorexia") OR Any Field: ("Anorexic") OR Any Field: ("Bulimia") OR Any Field: ("Bulimic") OR Any Field: ("Binge Eating Disorder") OR Any Field: ("Binge") OR Any Field: ("Binging") OR Any Field: ("Bingeing") OR Any Field: ("Purge") OR Any Field: ("Purging") OR Any Field: ("Purgeing") OR Any Field: ("Avoidant restrictive food intake disorder") OR Any Field: ("Avoidant/restrictive food intake disorder") OR Any Field: ("Eating Disorder Not Otherwise Specified") OR Any Field: ("Other Specified Feeding or Eating Disorder "))) AND ((Index Terms: ("Child Abuse") OR Index Terms: ("Child Neglect") OR Index Terms: ("Emotional Abuse") OR Index Terms: ("Verbal Abuse") OR Index Terms: ("Physical Abuse") OR Index Terms: ("Sex Offenses") OR Index Terms: ("Rape") OR Index Terms: ("Bullying") OR Index Terms: ("Cyberbullying") OR Index Terms: ("Domestic Violence")) OR (Any Field: ("Child Abuse") OR Any Field: ("Childhood Abuse") OR Any Field: ("Child Maltreatment") OR Any Field: ("Childhood Maltreatment") OR Any Field: ("Child Harm") OR Any Field: ("Abused Child") OR Any Field: ("Maltreated Child") OR Any Field: ("Maltreated Children") OR Any Field: ("Child Neglect") OR Any Field: ("Childhood Neglect") OR Any Field: ("Child Negligence") OR Any Field: ("Childhood Negligence") OR Any Field: ("Neglected Child") OR Any Field: ("Emotional Abuse") OR Any Field: ("Emotional Maltreatment") OR Any Field: ("Verbal Abuse") OR Any Field: ("Psychological Abuse") OR Any Field: ("Psychological Maltreatment") OR Any Field: ("Physical Abuse") OR Any Field: ("Physical



Maltreatment") OR Any Field: ("Physical Violence") OR Any Field: ("Sex Abuse") OR Any Field: ("Sexual Abuse") OR Any Field: ("Sex Exploitation") OR Any Field: ("Sexual Exploitation") OR Any Field: ("Rape") OR Any Field: ("Sex Assault") OR Any Field: ("Sexual Assault") OR Any Field: ("Bully") OR Any Field: ("Bullying") OR Any Field: ("Cyber Bullying") OR Any Field: ("Cyberbullying") OR Any Field: ("Peer Abuse") OR Any Field: ("Domestic Violence") OR Any Field: ("Domestic Abuse") OR Any Field: ("Family Violence") OR Any Field: ("Family Abuse"))))

## Embase

1. "Domestic Violence"/exp OR "Child Abuse" OR "Childhood Abuse" OR "Child Maltreatment" OR "Childhood Maltreatment" OR "Child Harm" OR "Abused Child" OR "Maltreated Child" OR "Maltreated Children"
2. "Child Neglect" OR "Childhood Neglect" OR "Child Negligence" OR "Childhood Negligence" OR "Neglected Child"
3. "Emotional abuse"/exp OR "Emotional Abuse" OR "Verbal Abuse" OR "Psychological Abuse" OR "Emotional Maltreatment" OR "Psychological Maltreatment"
4. "Physical abuse"/exp OR "Physical Abuse" OR "Physical Maltreatment" OR "Physical Violence"
5. "Sexual Abuse"/exp OR "Sexual Assault"/exp OR "Sex Abuse" OR "Sexual Abuse" OR "Sex Exploitation" OR "Sexual Exploitation" OR "Rape" OR "Sex Assault" OR "Sexual Assault"
6. "Bullying"/exp OR "Bully" OR "Bullying" OR "Cyber Bullying" OR "Cyberbullying" OR "Peer Abuse"
7. "Domestic Violence" OR "Domestic Abuse" OR "Family Violence" OR "Family Abuse"
8. "Eating disorder"/exp OR "Eating Disorder" OR "Eating Disorders" OR "Disordered Eating"
9. "Anorexia" OR "Anorexic"
10. "Bulimia" OR "Bulimic"
11. "Binge Eating Disorder"
12. "Binge" OR "Binging" OR "Bingeing"
13. "Purge" OR "Purging" OR "Purgeing"
14. "Avoidant restrictive food intake disorder" OR "Avoidant/restrictive food intake disorder"
15. "Eating Disorder Not Otherwise Specified"
16. "Other Specified Feeding or Eating Disorder"

## Actual Search:

'eating disorder'/exp OR 'eating disorder' OR 'eating disorders' OR 'disordered eating' OR 'anorexia' OR 'anorexic' OR 'bulimia' OR 'bulimic' OR 'binge eating disorder' OR 'binge' OR 'binging' OR 'bingeing' OR 'purge' OR 'purging' OR 'purgeing' OR 'avoidant restrictive food intake disorder' OR 'avoidant/restrictive food intake disorder' OR 'eating disorder not otherwise specified' OR 'other specified feeding or eating disorder'

AND

'domestic violence'/exp OR 'child abuse' OR 'childhood abuse' OR 'child maltreatment' OR 'childhood maltreatment' OR 'child harm' OR 'abused child' OR 'maltreated child' OR 'maltreated children' OR 'child neglect' OR 'childhood neglect' OR 'child negligence' OR 'childhood negligence' OR 'neglected child' OR 'emotional abuse'/exp OR 'emotional abuse'

OR 'emotional maltreatment' OR 'verbal abuse' OR 'psychological abuse' OR 'psychological maltreatment' OR 'physical abuse'/exp OR 'physical abuse' OR 'physical maltreatment' OR 'physical violence' OR 'sexual abuse'/exp OR 'sexual assault'/exp OR 'sex abuse' OR 'sexual abuse' OR 'sex exploitation' OR 'sexual exploitation' OR 'rape' OR 'sex assault' OR 'sexual assault' OR 'bullying'/exp OR 'bully' OR 'bullying' OR 'cyber bullying' OR 'cyberbullying' OR 'peer abuse' OR 'domestic violence' OR 'domestic abuse' OR 'family violence' OR 'family abuse'

## PILOTS

1. MAINSUBJECT.EXACT.EXPLODE("Child Abuse") OR "Child Abuse" OR "Childhood Abuse" OR "Child Maltreatment" OR "Childhood Maltreatment" OR "Child Harm" OR "Abused Child" OR "Maltreated Child" OR "Maltreated Children"
2. MAINSUBJECT.EXACT.EXPLODE("Neglect") OR "Child Neglect" OR "Childhood Neglect" OR "Child Negligence" OR "Childhood Negligence" OR "Neglected Child"
3. MAINSUBJECT.EXACT.EXPLODE("Emotional Abuse") OR "Emotional Abuse" OR "Verbal Abuse" OR "Psychological Abuse" OR "Emotional Maltreatment" OR "Psychological Maltreatment"
4. "Physical Abuse" OR "Physical Maltreatment" OR "Physical Violence"
5. MAINSUBJECT.EXACT.EXPLODE("Rape") OR "Sex Abuse" OR "Sexual Abuse" OR "Sex Exploitation" OR "Sexual Exploitation" OR "Rape" OR "Sex Assault" OR "Sexual Assault"
6. MAINSUBJECT.EXACT.EXPLODE("Peer Abuse") OR "Bully" OR "Bullying" OR "Cyber Bullying" OR "Cyberbullying" OR "Peer Abuse"
7. MAINSUBJECT.EXACT.EXPLODE("Family Violence") OR "Domestic Violence" OR "Domestic Abuse" OR "Family Violence" OR "Family Abuse"
8. MAINSUBJECT.EXACT.EXPLODE("Eating Disorders") OR "Eating Disorder" OR "Eating Disorders" OR "Disordered Eating"
9. "Anorexia" OR "Anorexic"
10. "Bulimia" OR "Bulimic"
11. "Binge Eating Disorder"
12. "Binge" OR "Binging" OR "Bingeing"
13. "Purge" OR "Purging" OR "Purgeing"
14. "Avoidant restrictive food intake disorder" OR "Avoidant/restrictive food intake disorder"
15. "Eating Disorder Not Otherwise Specified"
16. "Other Specified Feeding or Eating Disorder"

## Actual Search:

(MAINSUBJECT.EXACT.EXPLODE("Child Abuse") OR "Child Abuse" OR "Childhood Abuse" OR "Child Maltreatment" OR "Childhood Maltreatment" OR "Child Harm" OR "Abused Child" OR "Maltreated Child" OR "Maltreated Children" OR MAINSUBJECT.EXACT.EXPLODE("Neglect") OR "Child Neglect" OR "Childhood Neglect" OR "Child Negligence" OR "Childhood Negligence" OR "Neglected Child" OR MAINSUBJECT.EXACT.EXPLODE("Emotional Abuse") OR "Emotional Abuse" OR "Verbal Abuse" OR "Psychological Abuse" OR "Emotional Maltreatment" OR "Psychological Maltreatment" OR "Physical Abuse" OR "Physical Maltreatment" OR "Physical Violence" OR MAINSUBJECT.EXACT.EXPLODE("Rape") OR "Sex Abuse"

OR "Sexual Abuse" OR "Sex Exploitation" OR "Sexual Exploitation" OR "Rape" OR "Sex Assault" OR "Sexual Assault" OR MAINSUBJECT.EXACT.EXPLODE("Peer Abuse") OR "Bully" OR "Bullying" OR "Cyber Bullying" OR "bullying" OR "Peer Abuse" OR MAINSUBJECT.EXACT.EXPLODE("Family Violence") OR "Domestic Violence" OR "Domestic Abuse" OR "Family Violence" OR "Family Abuse") AND (MAINSUBJECT.EXACT.EXPLODE("Eating Disorders") OR "Eating Disorder" OR "Eating Disorders" OR "Disordered Eating" OR "Anorexia" OR "Anorexic" OR "Bulimia" OR "Bulimic" OR "Binge Eating Disorder" OR "Binge" OR "bingeing" OR "Bingeing" OR "Purge" OR "Purging" OR "purgeing" OR "avoidance restrictive food intake disorder" OR "avoidance/restrictive food intake disorder" OR "Eating Disorder Not Otherwise Specified" OR "Other Specified Feeding or Eating Disorder")

# Appendix C: Critical Review of the Literature - Quality Assessment

---

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (NIH)  
(adapted for use with mediators)

## Criteria

1. Was the research question or objective in this paper clearly stated?
2. Was the study population clearly specified and defined?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
5. Was a sample size justification, power description, or variance and effect estimates provided?
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
10. Were the mediator measures clearly defined, valid, reliable, and implemented consistently across all study participants?
11. Was the exposure(s) assessed more than once over time?
12. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
13. Were the outcome assessors blinded to the exposure status of participants?
14. Was loss to follow-up after baseline 20% or less?
15. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?

Quality Assessment Table

Key: CD = cannot determine, NA = not applicable, NR = not reported

Study	Criteria														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Craycraft (2014)	Yes	Yes	NA	Yes	No	Yes/CD	No	NA	No	No	NA	Yes	NA	No	No
Everill, Waller, & Macdonald (1995)	Yes	Yes	NR	No	No	No	No	NA	Yes	Yes	NA	Yes	NA	NA	No
Groleau et al. (2012)	Yes	Yes	NR	No	No	No	No	NA	Yes	No	NA	Yes	NA	NA	No
Hewett (2012)	Yes	Yes	NR	Yes	No	No	No	No	Yes	Yes	NA	Yes	NA	NA	No
Kong et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	No	NA	Yes	Yes	NA	Yes	NA	NA	No
Racine & Wildes (2015)	Yes	Yes	NR	Yes	No	No	No	NA	Yes	Yes	NA	Yes	NA	NA	No
Steiger et al. (2012)	Yes	Yes	NR	No	No	No	No	NA	Yes	No	NA	Yes	NA	NA	No
Sweetingham & Waller (2008)	Yes	Yes	NR	Yes	No	No	No	NA	Yes	Yes	NA	Yes	NA	NA	No
Tasca et al. (2013)	Yes	Yes	NR	Yes	No	No	No	NA	Yes	Yes	NA	Yes	NA	NA	No
Vrabel et al. (2010)	Yes	Yes	Yes	Yes	No	Yes/CD	No	NA	No	Yes	NA	Yes	NA	No	No
Waller et al. (2001)	Yes	Yes	NR	Yes	No	No	No	NA	Yes	Yes	NA	No	NA	NA	No

# Appendix D: Service Improvement Project - Clinical Psychology and Psychotherapy Author Guidelines

---

## 1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a meeting or symposium.

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This is a journal for those who want to inform and be informed about the challenging field of clinical psychology and psychotherapy.

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## 2. MANUSCRIPT CATEGORIES AND REQUIREMENTS

**Research articles:** Substantial articles making a significant theoretical or empirical contribution.

**Reviews:** Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

**Assessments:** Articles reporting useful information and data about new or existing measures.

**Practitioner Reports:** Shorter articles (a maximum of 1200 words) that typically contain interesting clinical material. These should use (validated) quantitative measures and add substantially to the literature (i.e. be innovative).

## 3. PREPARING THE SUBMISSION

### Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

### File types

Preferred formats for the text and tables of your manuscript are .doc, .docx, .rtf, .ppt, .xls. LaTeX files may be submitted provided that an .eps or .pdf file is provided in addition to the source files. Figures may be provided in .tiff or .eps format.

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Non-LaTeX users: Upload your manuscript files. At this stage, further source files do not need to be uploaded.

LaTeX users: For reviewing purposes you should upload a single .pdf that you have generated from your source files. You must use the File Designation "Main Document" from the dropdown box.

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4. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
5. Conflict of Interest statement;
6. Acknowledgments;
7. Abstract, Key Practitioner Message and keywords;
8. Main text;
9. References;
10. Tables (each table complete with title and footnotes);
11. Figure legends;

Figures and appendices and other supporting information should be supplied as separate files.

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Reference examples follow:

#### *Journal article*

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486.

doi: [10.1176/appi.ajp.159.3.483](https://doi.org/10.1176/appi.ajp.159.3.483)

#### *Book*

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

#### *Internet Document*

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from <http://www.youtube.com/watch?v=Vja83KLQXZs>

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Endnotes should be placed as a list at the end of the paper only, not at the foot of each page. They should be numbered in the list and referred to in the text with consecutive, superscript Arabic numerals. Keep endnotes brief; they should contain only short comments tangential to the main argument of the paper.

## Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and \*, \*\*, \*\*\* should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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3. **Numbers:** numbers under 10 are spelled out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
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Please note that the author is responsible for all statements made in their work, including changes made during the editorial process – authors should check proofs carefully. Note that proofs should be returned within 48 hours from receipt of first proof.

##### **Publication Charges**

**Colour figures.** Colour figures may be published online free of charge; however, the journal charges for publishing figures in colour in print. If the author supplies colour figures at Early View publication, they will be invited to complete a colour charge agreement in RightsLink for Author services. The author will have the option of paying immediately with a credit or debit card, or they can request an invoice. If the author chooses not to purchase color printing, the figures will be converted to black and white for the print issue of the journal.

##### **Early View**

The journal offers rapid publication via Wiley's Early View service. [Early View](#) (Online Version of Record) articles are published on Wiley Online Library before inclusion in an issue. Note there may be a delay after corrections are received before the article appears online, as Editors also need to review proofs. Once the article is published on Early View, no further changes to the article are possible. The Early View article is fully citable and carries an online publication date and DOI for citations.

#### **7. POST PUBLICATION**

##### **Access and Sharing**

When the article is published online:

- The author receives an email alert (if requested).

- The link to the published article can be shared for free with your contacts or through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- The corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

**Promoting the Article**

To find out how to best promote an article, click [here](#).

**Measuring the Impact of an Article**

Wiley also helps authors measure the impact of their research through specialist partnerships with [Kudos](#) and [Altmetric](#).

**8. EDITORIAL OFFICE CONTACT DETAILS**

Email: [CPPedoffice@wiley.com](mailto:CPPedoffice@wiley.com)

# Appendix E: Service Improvement Project - Questionnaire

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1. Where are you based? (If you are based at both sites, please choose the base you use most often):

☐ xxx (Recovery Team 1)

☐ xxx (Recovery Team 2)

2. What is your profession? (please choose one)

☐ Doctor

☐ Nurse

☐ Social Worker

☐ Student

☐ Support Worker

☐ Therapies (OT, physiotherapy, psychology, art therapy)

☐ Vocational Worker

3. Approximately how many people are on your caseload?

\_\_\_\_\_

Since the 5 Ps training you attended:

4. Have you used the 5 Ps framework when you have been talking directly with your service users? (please select): **YES/NO**

If you have answered **NO**, please move on to question 5.

If you have answered **YES**:

- Approximately how many service users have you used the 5 Ps with in this way? (please provide a number): \_\_\_\_\_
- On average, how useful have you found the 5 Ps when doing this? (please select one response)
  - ☐ Very useful
  - ☐ Somewhat useful
  - ☐ Not very useful

☐ Not at all useful

5. Have you attended any CPI reflective practice sessions? (please select): **YES/NO**

If you have answered **NO**, please move on to question 6.

If you have answered **YES**:

- Approximately how many sessions have you attended? (please provide a number): \_\_\_\_
  
- On average, how useful have you found reflective practice sessions? (please select one response)
  - ☐ Very useful
  - ☐ Somewhat useful
  - ☐ Not very useful
  - ☐ Not at all useful
  
- Have you used the 5 Ps framework in reflective practice sessions? (please select) **YES/NO**

If you have answered **NO**, please move on to question 5.

If you have answered **YES**:

- Approximately how many times have you used the 5 Ps in this way? (please provide a number): \_\_\_\_
  
- On average, how useful have you found using the 5 Ps in reflective practice? (please select one response)
  - ☐ Very useful
  - ☐ Somewhat useful
  - ☐ Not very useful
  - ☐ Not at all useful

6. Do you speak with anyone in CPI about your service users, outside of reflective practice? (please select): **YES/NO**

If you have answered **NO**, please move on to question 7.

If you have answered **YES**:

- On average, how useful have you found this? (please select one response)

- ☐ Very useful
- ☐ Somewhat useful
- ☐ Not very useful
- ☐ Not at all useful

- Have you used the 5 Ps framework when you have talked about service users with anyone in CPI, outside of reflective practice? (please select): **YES/NO**

If you have answered **NO**, please move on to question 7.

If you have answered **YES**:

- Approximately how many service users have you used the 5 Ps with in this way? (please provide a number): \_\_\_\_\_
- On average, how useful have you found the 5 Ps when doing this? (please select one response)

- ☐ Very useful
- ☐ Somewhat useful
- ☐ Not very useful
- ☐ Not at all useful

7. Have you used the 5 Ps framework when you have been thinking about your work with service users, outside of reflective practice or when speaking with someone in CPI? (please select) **YES/NO**

If you have answered **NO**, please move on to question 8.

If you have answered **YES**:

- In what other ways have you used the 5 Ps framework, outside of reflective practice or with someone from CPI?

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- Approximately how many service users have you used the 5 Ps with in this way? (please provide a number): \_\_\_\_\_
- On average, how useful have you found the 5 Ps when doing this? (please select one response)
  - ☐ Very useful
  - ☐ Somewhat useful

☐ Not very useful

☐ Not at all useful

8. If you have any comments about using the 5 Ps framework, please provide them below.

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# Appendix F: Service Improvement Project - Focus group interview schedule

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## **Introduction**

You've all been invited here today because you have all had training on the 5 Ps framework and using it in your work with your patients. Now it's been some time since the training, I'd like to find out your honest opinions about using this framework. Everything you say will be anonymous – I will write up a transcript of today and I will take out your names and any identifying information, and I will delete the recording once I have created the anonymised transcript. This means that nobody outside this room will be able to identify who said what – so please feel free to be honest as you would like to be.

## **How do you find using the 5 Ps?**

Prompts:        When is it useful (or not useful)?  
                      Are there times when it is less useful?  
                      Can you give me an example?  
                      Have you been trained to.../Do you prefer to formulate in other ways  
                      instead of using the 5 Ps?

## **Is using the 5 Ps difficult sometimes?**

Prompts:        What makes it difficult?  
                      Can you give me an example?  
                      What has/what would help you overcome these difficulties?

## **What makes it easier to use the 5 Ps?**

Prompts:        What would make it easier, if it isn't already?  
                      Is there anything that management or CPI could do that would        make  
                      things easier?

## **Endings**

Is there anything we have missed?  
What would you say is the most important take home message today about the 5 Ps?



# Appendix G: Main Research Paper – Journal of Pediatric Psychology Author Guidelines

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## Instructions to Authors

The *Journal of Pediatric Psychology* is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association. JPP publishes articles related to theory, research, and professional practice in pediatric psychology.

### Types of Manuscripts

- Original research, including case studies
- Review articles
- Invited commentaries

### Manuscript preparation: General Instructions

Full instructions for uploading data and files etc. are given on Manuscript Central at the website under Instructions for online

submission: [https://academic.oup.com/jpepsy/pages/Submission\\_Online](https://academic.oup.com/jpepsy/pages/Submission_Online).

### Organization of manuscripts

Manuscript Central will guide authors through the submission steps, including: Abstract, Keyword selection, and the Manuscript. The manuscript must contain an Introduction, Methods, Results, Discussion, Acknowledgements and Reference List.

*Length of manuscript:* Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Case reports should not exceed 20 pages.

Review articles should not exceed 30 pages. Invited commentaries should not exceed 4 pages.

The Journal of Pediatric Psychology no longer accepts brief reports but will accept manuscripts that are shorter in length than the 25 page manuscripts.

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

- (a) The academic degrees of authors should be placed on the title page following their names, and
- (b) a structured abstract of not more than 250 words should be included. The abstract should include the following parts:

- (1) Objective (brief statement of the purpose of the study);
- (2) Methods (summary of the participants, design, measures, procedure);
- (3) Results (the primary findings of this work); and
- (4) Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

*Informed consent and ethical treatment of study participants:* Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

*Clinical relevance* of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

*Terminology* should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

### Special instructions for types of manuscripts

(1) *Intervention studies/Randomized controlled trials/Non-randomized trials:* JPP is committed to enhancing the transparent reporting of all intervention studies. If you are submitting a manuscript of

a **randomized clinical trial (RCT)** to JPP, you are required to submit the CONSORT checklist and a flowchart of your research showing the steps found in the Consort E-Flowchart. Both the Consort E-Flowchart and a checklist of items to be included when reporting a randomized trial can both be found on <http://www.consort-statement.org>.

If you are submitting a **non-randomized trial** to JPP, you are required to follow the reporting elements of the TREND statement, <https://www.cdc.gov/trendstatement/index.html>.

For each submission (original and any revisions), authors should use and submit the appropriate checklist with their manuscript. Please use this one for RCTs

([https://academic.oup.com/DocumentLibrary/jpepsy/CONSORT\\_2010\\_Checklist\\_JPP.pdf](https://academic.oup.com/DocumentLibrary/jpepsy/CONSORT_2010_Checklist_JPP.pdf)) and this checklist for non-randomized trials

([https://academic.oup.com/DocumentLibrary/jpepsy/TREND\\_Statement\\_Checklist\\_JPP.pdf](https://academic.oup.com/DocumentLibrary/jpepsy/TREND_Statement_Checklist_JPP.pdf)).

Please clearly indicate the page numbers where each checklist item is reported in the manuscript.

Please upload this checklist as supplementary material when you submit your manuscript for consideration.

All intervention studies (RCTs and non-randomized trials) will undergo an additional review for transparent reporting conducted by the JPP Student Editorial Liaison. Review comments will be provided on the corresponding checklist. Authors will be required to address any identified reporting issues prior to publication.

(2) *Case Studies*: Although there may be some exceptions, most case studies should be sent to Clinical Practice in Pediatric Psychology (CPPP). Single-subject studies that employ rigorous A-B-A-B designs and/or statistical strategies can be sent to JPP. All others will probably fit better with CPPP. Case reports should not exceed 20 pages. Case reports are appropriate to document the efficacy of new treatment applications; to describe new clinical phenomena; to develop hypotheses; to illustrate methodological issues, difficult diagnoses, and novel treatment approaches; and to identify unmet clinical or research needs. Guidelines for case study submissions can be found in Drotar, D. (2009). Editorial: Case Studies and Series: A Call for Action and Invitation for Submissions, *Journal of Pediatric Psychology*, 34, 795-802; Drotar, D. (2011). Editorial: Guidance for Submitting and Reviewing Case Reports and Series in the *Journal of Pediatric Psychology*, 36, 951-958.

Guidelines for Single Subject Studies: Please read Rapoff, M. & Stark, L. (2008). Editorial: Journal of Pediatric Psychology Statement of Purpose: Section on Single-Subject Studies.

(3) *Measurement development and validation articles*: For additional guidance please read, Holmbeck, G. & Devine, K. (2009) Editorial: An Author's Checklist for Measure Development and Validation Manuscripts.

(4) *Review articles*: Please consult the recent editorial (New Guidelines for Publishing Review Articles in JPP) which describes new guidelines for review articles, and the Checklist for Preparing and Evaluating Review Articles.

(a) *Topical reviews*: Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. They are limited to 2,000 words, contain no more than 2 tables or figures, and have an upper limit of 30 references. Supplementary online material (e.g., additional tables) may be considered on a case by case basis.

(b) *Systematic reviews*: Systematic reviews should not exceed 30 pages. Authors are required to attach the PRISMA checklist and flow diagram as supplementary material for each submission. Authors can find the PRISMA checklist and flow diagram in downloadable templates that can be re-used at this URL, <http://www.prisma-statement.org/PRISMAStatement/Default.aspx>. Authors of systematic reviews that do not include a meta-analysis must provide a clear statement in the manuscript explaining why such an analysis is not included for all or relevant portions of the report.

(5) *Invited commentaries*: Commentaries are invited on all topics of interest in pediatric psychology, and should not exceed 4 pages, including references. Un-invited commentaries will not be considered.

(6) *Historical Analysis in Pediatric Psychology* is a special series of papers devoted to the history of pediatric psychology. Authors interested in submitting a paper for this series should contact the Editor of JPP to discuss potential papers prior to submission. There is no deadline for these papers (they may be submitted anytime). All submissions will be peer reviewed and should comply fully with the JPP Instructions to Authors. Papers in this series should be tightly focused contributions that expand our understanding of the roots, evolution, and/or impact of pediatric psychology as a discipline. Manuscripts may focus on the influence of individuals, published works, organizations, conceptualizations, philosophies or approaches, or clinical and professional activities. Successful papers should articulate a clear purpose/question and develop a compelling argument for the topic. Contributions should include a breadth of coverage, such that contradictory data are included and potential biases acknowledged. Historical analysis is more than a recounting of the "facts" and should include a thoughtful and scholarly interpretation of the subject matter. Papers should rely on primary sources and must be clearly and appropriately referenced. Supplemental materials to accompany the article may be posted online.

## Additional Guidance

The following links provide additional guidance for authors and reviewers: [Editorial Policy](#), [Authors' Checklist](#), [Guidelines for Reviews](#), [Suggestions for Mentored Reviews](#), ["People First."](#) [NIH policy](#), [Replication of research](#), [Duplicate and redundant policies](#), [Conflict of interest](#).

See the following articles for detailed guidance concerning preparation of manuscripts: [Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the Journal of Pediatric Psychology](#); [How to Write a Convincing Introduction](#); [Methods: Editorial: How to Report Methods in the Journal of Pediatric Psychology](#); [Results and Discussion: Editorial: How to Write an Effective Results and Discussion Section for the Journal of Pediatric Psychology](#).

## Funding

Details of all funding sources for the work in question should be given in a separate section entitled "Funding." This should appear before the "Acknowledgements" section.

The following rules should be followed:

- The sentence should begin: "This work was supported by . . ."
- The full official funding agency name should be given, i.e. "the National Cancer Institute at the National Institutes of Health" or simply "National Institutes of Health," not "NCI" (one of the 27 subinstitutions) or "NCI at NIH" ([full RIN-approved list of UK funding agencies](#))
- Grant numbers should be complete and accurate and provided in parentheses as follows: "(grant number xxxx)"
- Multiple grant numbers should be separated by a comma as follows: "(grant numbers xxxx, yyyy)"
- Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)
- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]."

Oxford Journals will deposit all NIH-funded articles in PubMed Central.

See [https://academic.oup.com/journals/pages/open\\_access/funder\\_policies/niH](https://academic.oup.com/journals/pages/open_access/funder_policies/niH) for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above

## Color Figure Charges

Authors are charged for the print reproduction of color figures. The cost is \$600 / €525 / £325 per color page. Figures can be published in black and white in the print edition and in color online for free. If you choose this option, please ensure that your figures are clear and readable in both black and white and color.

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# Appendix H: Main Research Paper – Health Research Authority Approval

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**Health Research Authority**

Ms Madeline Harris  
Dept of Clinical Psychology, 10 West  
University of Bath  
Bath  
BA2 7AY

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

07 April 2017

Dear Ms Harris

## Letter of HRA Approval

<b>Study title:</b>	<b>Parental Illness Perceptions in Type 1 Diabetes and JIA</b>
<b>IRAS project ID:</b>	<b>216483</b>
<b>REC reference:</b>	<b>17/LO/0361</b>
<b>Sponsor</b>	<b>University of Bath</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

### **Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

## Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

## After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website. **End of option 1**

## Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

### **HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **216483**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede  
Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: Professor Jonathan Knight, Sponsor Contact

Dr Elinor Griffiths, University Hospitals Bristol NHS Foundation Trust,  
Lead NHS R&D Contact

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Contract/Study Agreement [Statement of Activities]		07 April 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Liability insurance confirmation]		29 January 2017
IRAS Application Form [IRAS_Form_08022017]		08 February 2017
IRAS Application Form XML file [IRAS_Form_08022017]		08 February 2017
IRAS Checklist XML [Checklist_07032017]		07 March 2017
Letter from sponsor [Sponsorship approval]		29 January 2017
Non-validated questionnaire [Demographics and clinical information]	v.1	29 January 2017
Other [Participant debriefing information]	v.1	29 January 2017
Other [Participant debriefing information (if participant chooses to withdraw)]	v.1	29 January 2017
Other [2nd supervisor CV]		29 January 2017
Other [Schedule of events]		29 January 2017
Other [Statement of activities]		29 January 2017
Other [Email from M Harris]		12 February 2017
Other [Schedule of Events]		07 April 2017
Participant information sheet (PIS) [PIS and Consent form (T1D)]	4	07 April 2017
Participant information sheet (PIS) [PIS and Consent form (JIA)]	4	07 April 2017
Research protocol or project proposal [Protocol]	v.1	29 January 2017
Summary CV for Chief Investigator (CI) [CV MH]		29 January 2017
Summary CV for student [CV MH]		29 January 2017
Summary CV for supervisor (student research) [CV CD]		29 January 2017
Summary, synopsis or diagram (flowchart) of protocol in nontechnical language [Lay Summary]	v.1	29 January 2017
Validated questionnaire [CBIPQ, PHQ-9, GAD-7]		

## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in**

**England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Professor Jonathan Knight

Tel: 01225383162

Email: pro-vc-research@bath.ac.uk

#### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor intends to use a Statement of Activities as the form of agreement with participating NHS organisations.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study.
Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	No application for external funding made. No funds will be provided to the participating organisation to support this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments



5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Favourable Opinion with conditions issued 24 February 2017. Favourable Opinion with conditions met issued 08 March 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

## Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

This is a non-commercial student (Clinical Psychology Doctorate (DClinPsy)) study and there is one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

## Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

### Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A PI is expected at the participating organisation.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

### HR Good Practice Resource Pack Expectations

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

As a non-commercial study undertaken by local staff, it is unlikely that letters of access or honorary research contracts will be applicable, except where local network staff employed by another Trust (or University) are involved (and then it is likely that arrangements are already in place). Where arrangements are not already in place, network staff (or similar) undertaking any research activities that may impact on the quality of care of the participant, would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members undertaking activities that do not impact on the quality of care of the participant (for example, administering questionnaires), a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

### Other Information to Aid Study Set-up

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

# Appendix I: Main Research Paper – University of Bath Ethical Approval

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Ethics 17-109

Nathalia Gjersoe

Tue 16/05/2017 13:33

To: Madeline Harris <M.G.Harris@bath.ac.uk>;  
Cc: Cara Davis <C.Davis@bath.ac.uk>;

Dear Madeline,

**Reference Number 17-109: Parental Illness Perceptions in Type 1 Diabetes  
and JIA**

Apologies for the delay getting this response to you. The ethics committee have considered your ethics proposal for the study above and have given it full ethical approval.

Best wishes with your research.

Dr Nathalia Gjersoe

Chair, Psychology Ethics Committee

# Appendix J: Main Research Paper – Carer BIPQ Permissions

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**From:** Elizabeth Broadbent <[e.broadbent@auckland.ac.nz](mailto:e.broadbent@auckland.ac.nz)>

**Sent:** 28 September 2016 21:33

**To:** Madeline Harris

**Subject:** Re: Permissions - adapted BIPQ

Sure that is fine

Kind regards

Liz

**Elizabeth Broadbent (PhD)**

Associate Professor in Health Psychology

Dept of Psychological Medicine

Faculty of Medical and Health Sciences

The University of Auckland

New Zealand

[e.broadbent@auckland.ac.nz](mailto:e.broadbent@auckland.ac.nz)

[google scholar](#)

On 29/09/2016, at 4:56 am, Madeline Harris <[M.G.Harris@bath.ac.uk](mailto:M.G.Harris@bath.ac.uk)> wrote:

Dear Dr Broadbent,

My name is Maddy Harris, and I'm a Clinical Psychologist in Training at the University of Bath. One of the projects I am hoping to complete for my doctorate is to do with parental illness perceptions of their child's illness. With this in mind, I wanted to email and ask for your permission to use an adapted version of the BIPQ for use with caregivers? The adaptations I have in mind follow the explanation given in your paper co-authored with Amy Richardson and Randall Morton published in 2015 – the one which explores caregiver's illness perceptions when a family member has a cancer diagnosis. I have attached a file with the adaptations I had in mind, in case you would like to see these before deciding whether to give your permission.

If you have any questions or concerns then please don't hesitate to get in touch. Thank you very much for your help and your time.

With very best wishes,

Maddy

**Maddy Harris**

Clinical Psychologist in Training

University of Bath

<caregiver BIPQ draft.docx>